Brenda Bogaert

Patient Life Empowerment : Toward a Patient Developed Approach

Integrating epistemic contributions of refractory epilepsy patients in France and in China through a method *with* emotions and a method *with* capabilities

Le patient acteur de sa vie : vers une approche collaborative avec le patient

Intégration des contributions épistémiques de patients épileptiques pharmaco-résistants en France et en Chine, à travers une méthode avec les émotions et une méthode avec les capacités

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Le patient acteur de sa vie :
vers une approche collaborative avec le patient

*Intégration des contributions épistémiques de patients épileptiques pharmaco-résistants en France et en Chine à travers deux méthodes, l'une basée sur les émotions, l'autre sur les capacités******

La notion du patient acteur est aujourd'hui mise en valeur. Elle apparaît comme un droit et induit des responsabilités. Nous demandons au médecin de faire participer le patient et au patient d'apprendre et de gérer sa maladie. Néanmoins, la relation médecin-patient continue d'être source de souffrance pour le patient, le soignant, et sa famille. Créer un environnement propice pour une participation de tous les patients est aujourd'hui une priorité pour les politiques publiques. Afin de développer notre approche du patient acteur, nous proposons deux méthodes en philosophie inspirées de Martha Nussbaum, une méthode *basée sur* les émotions, et une méthode *basée sur* les capacités. Grâce à sa contribution, nous développons une approche collaborative avec le patient, le *patient acteur de sa vie*. Nous considérons la vie des patients dans son ensemble : c'est-à-dire les relations avec leurs familles, leurs médecins, et dans leur quotidien. Nous plaidons ainsi pour une responsabilité sociale plus large pour aider les patients à s'épanouir.

Mots-clés : patient acteur, capabilités, émotions, Nussbaum, épilepsie, injustice épistémique

Patient Life Empowerment: Toward a Patient Developed Approach

Integrating epistemic contributions of refractory epilepsy patients in France and China through a method with emotions and a method with capabilities

The notion of patient empowerment is valued today as both a right and a responsibility. We ask doctors to help the patient participate and the patient to learn about and to manage the disease. However, the doctor-patient relationship continues to be a source of suffering for the patient, the healthcare provider, and for the family. An urgent task for public policymakers today is to create a facilitating environment for all types of patients. We propose two methods in philosophy inspired by American philosopher Martha Nussbaum, a method *with* emotions and a method *with* capabilities, to develop our patient empowerment approach. With her contribution, we develop a collaborative approach with our patients, the *patient life empowerment approach*. We consider the patient's life holistically, including in relationships with their families, their doctors, and in society. With our approach, we advocate for a larger social responsibility to help patients to flourish.

Key words: patient empowerment, capabilities, emotions, Nussbaum, epilepsy, epistemic injustice

(**Un résumé substantiel en français est à la fin du document*)

To persons with epilepsy and their families...

And to my mom…

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List of acronyms

AED	Anti-Epileptic Drugs
ANSEM*	Agence nationale de l'évaluation et de la qualité des établissements et services sociaux et médico-sociaux
CA	Capabilities Approach
EAEC	European Association of Epilepsy Centers
EEG	Electroencephalography
EBM	Evidence-Based Medicine
EPHAD	Etablissement d'hébergement pour personnes âgées dépendantes
FAM	Foyer d'accueil médicalisé
FLE	Family Life Empowerment
HAS	Haute Autorité de santé
ILEA	International League Against Epilepsy
IME	Instituts médico-éducatifs
LEP	Life Empowered Patient
PAM	Patient Activation Measure
PCC	Patient-Centered Care
PLE	Patient Life Empowerment
PP	Patient-as-Partner
PWE	Patients with Epilepsy
SUDEP	Sudden Unexpected Death in Epilepsy
VNS	Vagus Nerve Stimulation

(*****Since April 1st, 2018, ANSEM has been integrated into HAS)

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Introduction

New forms of patient participation are emerging. Patient associations are playing an increasingly political role in healthcare policy development, with integration into both formal and informal cadres of patient support. Patient experts are becoming teachers to other patients and to future doctors. Approaches such as patient-centered care seek to put the patient at the center of the healthcare plan. New models in medical schools seek to integrate patient experience into medical training.[1] Legislative frameworks in several countries, including France[2], have responded to ensure that healthcare providers work actively with patients in daily practice.

Meanwhile the doctor-patient relationship continues to be described as one of mistrust, anxiety, and dual suffering. Much patient dissatisfaction is due to breakdowns in the doctor-patient relationship.[3] Conflictual patient-doctor relationships have also been correlated with poor healthcare outcomes.[4] At the same time, physician burn-out is becoming an increasing problem, leading to inadequate patient participation, medical errors, and poor healthcare outcomes.[5] As the doctor-patient relationship is a complex topic that means different things to different people, research in the area remains fragmented. Most research tends to focus on facets of the consultation such as the interpersonal or communication skills of the doctor,[6] or the characteristics of a successful doctor-patient relationship, such as trust.[7] An urgent task for public policy today is how to create the facilitating environment to ensure that *all* types of patients are capable of participating in their healthcare decision-making.

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[1] Karazivan, Philippe, Vincent Dumez, Luigi Flora, Marie-Pascale Pomey, Claudio Del Grande, Djahanchah Philip Ghadiri, Nicolas Fernandez, Emmanuelle Jouet, Olivier Las Vergnas, and Paule Lebel. 2015. *The Patient-as-Partner Approach in Health Care: A Conceptual Framework for a Necessary Transition.* Academic Medicine 90 (4): 437–41

[2] Law n° 2002-303 du 4 mars 2002 relative to patient rights and the quality of the healthcare system. 2002-303

[3] Ha, J.F., Longnecker, N., 2010. *Doctor-patient communication: a review*. Ochsner J 10, p. 38

[4] Chipidza, F.E., Wallwork, R.S., Stern, T.A., 2015. *Impact of the Doctor-Patient Relationship*. Prim Care Companion CNS Disord 17

[5] Dyrbye, L.N., Shanafelt, T.D., 2011. *Physician Burnout: A Potential Threat to Successful Health Care Reform*. JAMA 305.

[6] Ridd, M., Shaw, A., Lewis, G., Salisbury, C., 2009. *The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives*. Br J Gen Pract 59, e116.

[7] O'Neill, O., 2002. *Autonomy and trust in bioethics*, Gifford lectures. Cambridge University Press, Cambridge ; New York.

Is patient empowerment the answer to this dilemma? This idea has emerged both due to changing philosophical and political ideas of the individual's rights to participation as well as a certain form of liberalism seeking to put responsibility on the individual patient for healthcare outcomes. The so-called empowered patient, helping the doctor to find a personalized treatment plan, is concurrently being promoted as a right and a responsibility. As a society, we assume that patients wish for active roles in their healthcare plans, but what this role consists in is largely dictated by economists and healthcare institutions that seek outcomes in terms of reduced hospital admissions and other healthcare costs. In these discussions, the patient's view on their participation has often been silenced. What does patient empowerment mean for the patient and for the family? What are they seeking by being empowered in their healthcare plan? What result are they looking for in their healthcare?

This thesis seeks to correct an epistemic injustice[8]: the absence of patient contributions to this discussion. This project was developed by soliciting patient and healthcare provider contributions in both informal and formal spaces of healthcare delivery (hospitals but also patient associations). It will identify both the blocking and enabling factors that enable patient empowerment as understood by the patient.

We have chosen to focus on one particular group of patients, refractory epilepsy patients.[9] In this thesis, refractory epilepsy will serve as a borderline case of the patient empowerment conception, in order to show us the full potential of such a concept for *all* patients. Refractory epilepsy represents approximately one-third of epilepsy patients and the term refers to those patients whose seizures[10] are unable to be completely stabilized[11] by anti-epileptic drugs (AEDs). They are a group who must live with considerable risk due to this non-stabilization, with restrictions in work and leisure activities. The treatment plan remains uncertain in these cases and is mostly trial and error. These patients are either the ideal candidates for patient empowerment, or those who may not be able, or may not wish to participate in healthcare decision making, due to these difficulties. They are also borderline cases in the sense that, despite their best efforts to find ways to manage their

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[8] Fricker, M., 2009. *Epistemic injustice: power and the ethics of knowing*, 1. publ. in paperback. ed. Oxford University Press, Oxford. p. 1

[9] See Appendix for the definition of refractory epilepsy as well as other related terms about epilepsy.

[10] Seizure is the English word used to describe "crises d'épilepsie" in French. The word *crise* used in French suggests a more neutral signification than seizure, which in its etymology suggests an act of seizing, whereas some seizures (such as absence seizures) may not involve visible acts of seizing.

[11] Stabilization is the main goal of epilepsy treatment, as it allows seizures to disappear from the person's daily life. Patients celebrate milestones such as "1 year seizure free."

disease, as well as considerable investment by their healthcare provider to find the right treatment plan, stabilizing their epilepsy may never be fully possible. We have chosen this particular group of patients to show the full potential of the patient life empowerment conception not just for those lucky patients who have been stabilized by medication, or have found effective self-management strategies, but also for those who continue to live with considerable difficulties in their daily lives because of their disease.

The research took place in two countries, France and China. These two countries have considerable differences in healthcare infrastructure and resources to support patients, as well as differing visions of patient participation. Rather than comparing these differences, we will seek convergences among refractory epilepsy patients' experiences of disease in these two countries to understand commonalities among this group of patients across sites. We will noticeably seek convergences among these patients in Chapter 2 of this thesis when we discuss the emotion of *fear*.

Through several methods developed to promote epistemic contributions by patients, a method *with* emotions and a method *with* capabilities, we will seek the patient's perspective in order to move toward a patient developed approach to empowerment. We aim to provide a critical means of thinking about patient empowerment from the perspective of the patient and to provide new tools to solicit the patient's perspective. This thesis also has a practical aim: to provide suggestions and inspirations for institutions to model their healthcare plans based upon the patient developed approach we propose.

This research has largely been developed with input from American philosopher Martha Nussbaum's theories on emotions and on the capability approach. We were also inspired by other philosophers – namely Miranda Fricker's concept of epistemic injustice, as well as other disciplines, including sociologists such as Zygmunt Bauman, which helped us understand empowerment in the context of today's *liquid societies*, or anthropologists such as George Marcus, which helped us to define the idea of fieldwork for this project. This research is therefore an interdisciplinary one, anchored in the field and inspired from philosophy but also other disciplines.

The thesis is structured along the following lines: in Chapter 1, we will first introduce the current definitions of patient empowerment. The purpose of this investigation will be to show why they are insufficient to take into account the patient's perspective and for what reasons they are being promoted today. This will include reviewing existing definitions of patient empowerment as well as other formulations (patient activation, patient engagement, patient-partnership), as well as the biomedical claims behind patient

empowerment. These preliminary investigations will also help us to understand why the current conceptions might be a case for epistemic injustice.

From Chapter 2, we will begin seeking the patient's perspective to help move us toward the patient life empowerment approach. As our methods are integrated into the results, they have been incorporated into each chapter (Chapters 2 and 3) rather than forming a separate methodology chapter. In Chapter 2, we will develop our method *with* emotions, inspired by Martha Nussbaum's philosophy of emotions, to help solicit the epistemic contributions of patients. We will outline the advantages as well as limitations of this method and the field sites where it was used. In the second part of Chapter 2, we will identify what our method *with* emotions has achieved.

In Chapter 3, we will continue seeking the patient's perspective by introducing our method *with* capabilities. Largely inspired from Martha Nussbaum's contributions to the capabilities approach, we will use several capabilities in her list as *epistemic tools* to seek the patient's perspective. As these are the pertinent capabilities that were identified by patients themselves through our fieldwork, the approach will be used to further analyze these contributions coming from patients in order to propose our patient life empowerment approach. We will highlight the strengths of our proposal over existing patient empowerment definitions. We will also discuss what this approach might mean for institutions (healthcare, but also a wider cadre of institutions). We will also introduce the family life empowerment approach and its implications of our institutions.

As the patient life empowerment approach is an ambitious goal for public policy, we will end the thesis with a case study of one institution able to realistically promote the patient life empowerment approach. The purpose of this final investigation will be to understand what elements might need to be present to enable such an approach on the ground in other institutions. This section is intended for inspiration rather than a cookie-cut answer of how to promote the patient life empowerment approach; however, by highlighting what made the approach possible, we hope to move toward future possibilities for other institutions.

Chapter 1

Patient Empowerment Under the Microscope

"There is only one Cardinal Rule: One Must Always Listen to the Patient."

Oliver Sacks[12]

[12] Sacks, Oliver. 1992. *Migraine*. Rev. and expanded. Berkeley: Univ. of California Press. p. 252

1.1. Introduction

In this preliminary chapter, we will discuss why current definitions of patient empowerment are insufficient to integrate the patient's perspective. We will analyze the philosophies and social movements underpinning the empowerment movement and their applications to the healthcare context. We will also investigate the current definitions of patient empowerment and discuss why patient empowerment cannot only be conceived of in the doctor-patient relationship or on the basis of autonomy.

Secondly, we will be investigating how patient empowerment discussions have been justified based upon a number of biomedical claims. The purpose of these investigations will be to put "patient empowerment under the microscope." What we mean by this metaphor is that we will seek to provide a critical analysis of patient empowerment, in its various formulations and origins, in order to unpack the biomedical and policy priorities behind it.

This chapter serves as a preliminary chapter that will provide the first step toward the approach we will defend in this thesis: the *life empowered patient (le patient acteur de sa vie)*. We will be introducing Miranda Fricker's concept of *epistemic injustice*[13] to better understand why patient empowerment under the biomedical model does not reflect patient experiences and why this might be a matter of injustice.

In the final part of this chapter, we will also investigate the other formulations that have been proposed for the patient's increasing role. In the first place, we will discuss why patient empowerment and patient-centered care (PCC) are complementary, but also different, and why the PCC model cannot be used to encompass the patient empowerment approach. We will then highlight the major formulations that have been proposed either as a complement to empowerment, such as *empowerment caring*, or as an alternative to empowerment (*patient activation*, *patient engagement*, and *patient partnership*). We will discuss the various limitations of these concepts and why they will not be used to develop our approach. Based upon these building blocks, in the last part of this chapter, we will highlight our use and definition of the field that we will mobilize in subsequent chapters.

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[13] Fricker, M., 2009. *Epistemic injustice: power and the ethics of knowing*, 1. publ. in paperback. ed. Oxford University Press, Oxford. p. 1

1.1.1. Strategic and Practical Aims of Using the Words Patient Empowerment

Let us begin our discussion by highlighting our priority in the use of the term "patient empowerment" over other formulations proposed (such as *patient activation* or *patient engagement*). Our choice of this terminology has both a practical and a strategic aim. In the first place, *patient empowerment* is the most widely recognized term in English to describe the image of a changing role for the patient in both academic literature and in policy discussions.[14] While other conceptions are increasingly gaining ground in attempts to move beyond the limitations of the empowerment concept, they are problematic for a variety of reasons, as we will show in the last part of this chapter. Under these circumstances, we believe that patient empowerment remains the most flexible word for our purposes.

However, we also have a strategic aim of using the formulation *patient empowerment*. Empowerment in its etymology has two dimensions, the idea of *power*, and the *learning process* to accede to that power.[15] It has come to be seen as both a process and an outcome. However, it was not until the 1970s, and notably diverse civil rights movements that the term *empowerment* was seen by social and political groups as a way to transform established practices and institutions. While the disadvantage of this idea is that it is in turn associated with other empowerment movements that have different priorities and aims, the word *empowerment* is the only word that fully embraces the concurrent social transformations in the idea of the patient *and* as a person in society, looking for new ways and forms of participation. It therefore allows us to see the idea of *empowerment* not only as directed to healthcare, but also as part of wider philosophical, social, and political movements. As our *patient life empowerment* approach also builds from patients' desires to integrate and participate in society, it aligned with the aims of this research project.

There remains a problem of translation, however, in the use of the word *empowerment* for this research project (and in particular for a French-speaking audience). The most widely used term in French to describe patient empowerment is *patient acteur*

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[14] Since the 1980s, the term was taken up by academics to signal new approaches and a rupture with older approaches (such as Parson's sick role) now viewed as paternalistic. We will question whether or not this term has moved us any farther from paternalistic approaches throughout this introductory chapter. For a history of the term, see: Bacqué, M.-H., Biewener, C., 2013. *L'empowerment, un nouveau vocabulaire pour parler de participation ?* Idées économiques et sociales 173, p. 26.
[15] *Ibid.*, p. 25.

(although some go as far as to call it *empouvoirment*[16]). This idea of *patient acteur* (patient actor) has a number of advantages, but also disadvantages when translated into English. In the first place, it is a *double entendre*: it can be understood as the patient who is acting (in the sense of agency), but also the patient who is acting (in the sense of theater). Translating this idea directly could lead to some misconceptions that the patient's role is somehow fraudulent, or play acting, and not a real role. Another translation of *acteur* could be *player*; however, we have again another double entendre in the same direction.[17] As we will see, patient empowerment seeks an active role for the patient and by extension for the person in society.

However, the advantage of the French formulation over the English one is that it allows the patient to be seen as an actor, but not necessarily the main actor. For instance, the patient actor can also be an actor alongside the doctor or the family, who are also actors. This is an advantage for seeing the patient not as a fully autonomous individual, but as one of several actors in a relationship, and it closely aligns with the approach we wish to defend. However, because of these double entendres, there remains no easy choice to translate *patient acteur* into English.

The same goes for translating the idea of *empowerment* into French: it has been translated as power over (*authorizer*) but also giving power to (*rendre capable*).[18] Both formulations could be interesting for our discussion, but their ambiguity at least partly explains why a more neutral term has been found in French. These are the practical and strategic reasons that we have chosen to use the formulation of patient empowerment in this thesis. Let us now unpack its various origins and inspirations.

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[16] Other translations include: *capacitation*, *autonomisation* and *pouvoir d'agir*. The problem with translations such as *autonomisation* and *capacitation* is that do not take into account the dimension of power; while *pouvoir d'agir* does not take into account how to arrive at this result. No translation is fully satisfactory *Ibid.*, p. 25. However, it was suggested by the thesis jury that the term *gain d'agentivité* may be a possible translation.

[17] The benefit however of this double entendre is to see patients as capable of creative activity. See Nussbaum's list of central capabilities in Chapter 3 as well as our example of how one institution allows patients creative "play" into their patient life empowerment healthcare plan.

[18] See the issues of authorizing/give power in the patient empowerment discussion in this chapter.

1.2. Patient Empowerment in History

Before introducing the current definitions of patient empowerment, it will first be interesting to understand if patient empowerment is contemporary. While it may seem "modern" to discuss patient empowerment, with an image of moving from a paternalistic doctor to one of—at least equal footing—with the patient, today's call for patient participation in healthcare is by no means new. When combining the words "patient" and "empowerment," we are not really describing a new idea, but rather adding to an ongoing discussion about the role of doctors in society and how this role is expressed in our institutions. It is thus worth looking at several historical visions of the doctor and patient's roles before starting our discussion of more recent empowerment movements.

The historical narrative we deliver is largely Western-centered, as we rely on historians who have sought to discover patient empowerment's origins in Western Europe and North America. This is a methodological choice on historians' part. This can be justified as empowerment grew from civil rights movements in the United States. However, by highlighting their ideas, we are not suggesting that patient participation did not occur and cannot be found in other contexts and cultures.

Through this brief historical narrative, we will see that patient empowerment has been called for both in the interests of the patient and in the interests of society. These interests have intertwined with our misgivings about medicine's abilities to heal us through their (imperfect) knowledge of our individual bodies and experiences, in spite of and because of the dominant medical model of disease of the day. We will highlight examples of patient empowerment from Antiquity, the Renaissance, as well as from the 18th century. This is not an inclusive historical reading, but rather a reading with an objective in mind: to understand the historical moments where there have been calls for greater patient involvement.

We will highlight a certain number of proposals developed by historians of patient empowerment. These include an active role for the patient in healthcare management (Greek and Roman models); a changing power relationship between healthcare provider and the patient (the Renaissance model); and "self-help" methods prioritized over seeking the assistance of the doctor (18th century models in the United States). All of these models have been identified by historians as "patient empowerment"; however they are also a reflection of our current conceptions (and confusions) over patient empowerment. It is not

to be expected that people saw these preferences or realities as something like how we perceive patient empowerment today, even if the resemblances are striking. In particular, it is worth remembering that access to medical care remained a privilege rather than a right for much of history (and remains so today in many countries).

In addition, Pierron highlights that the term *patient* as we currently understand it is linked to the rise of modern biomedicine.[19] According to him, the hermeneutical framework of modern biomedicine created the figure of the patient, whereby the *patience* of the *sick person* waiting for eternal life instead became the *patient* expecting a longer and healthier life.[20] If we look at the etymology of the word patient in terms of a sick person who is cared for by a doctor, we can see this formulation for the patient starting only from the 14th century.[21] Therefore this historical narrative is to be taken with caution when combining our contemporary ideas of the patient as a *subject* of rights and as a *user* of a healthcare service with the aim of prolonging a longer and healthier life.

The Greeks: Self-sufficiency

According to historians, the idea of patient empowerment in ways resembling our modern preoccupations can already be seen from the Greek enlightenment (5th century B.C.), which saw the development of a medical system based upon natural observation[22], abandonment of magical and religious justifications for disease, and an important role for the patient in disease management through self-sufficiency. For Plato, health could be encouraged through self-control. He believed that a sound bodily health provided the means for sound healthy thinking (*sophrosoyne* or soundness of mind).[23] In return, Aristotle, a doctor's son, called for the systematic observation of nature. For Hippocrates, man was governed by the same laws as the cosmos and he saw the human body as a microcosm in the grand order of nature (*macroscose*).

These philosophies translated into a practice of medicine that should rationally investigate the workings of the body in its natural environment. Health came to be seen as equilibrium, a balance between the body and the external environment. With these

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[19] Pierron, J.-P., 2007. *Une nouvelle figure du patient ? Les transformations contemporaines de la relation de soins.* Sciences sociales et santé 25, p. 52
[20] *Ibid.*, p. 52.
[21] PATIENT : *Etymologie de PATIENT*, n.d. URL https://www.cnrtl.fr/etymologie/patient (accessed 7.26.19).
[22] Hippocrates uses the example of epilepsy in the "Sacred Disease" to show its originals as natural, not supernatural. Porter, Roy. 1999. *The Greatest Benefit to Mankind: A Medical History of Humanity from Antiquity to the Present*. 1. paperback ed. London: Fontana Press. p. 53
[23] *Ibid.*, p. 64

thinkers, and especially Hippocrates, medicine began to be based upon observation and experience rather than superstition. Athens was the first city during this time to support full-time healers and according to Plato, Hippocrates was willing to train all those who would pay.[24] The medical model put forward by him promoted the active participation of persons in their healthcare through the ideal of self-sufficiency (*autarkeia*).[25] Protagoras defined *autarkeia* as a state of being in which one is not dependent on others.[26] Thus in Greek thought, there was considerable emphasis on the person to be independent. This translated into a certain vision of "health management" for the Greeks. Hippocrates stated, *"an intelligent man understands that health is a person's most valuable possession and must know how to help himself with his own thoughts in the case of illness."*[27] The healthcare model in other words meant learning how to take care of oneself.

In turn, the physician was there to help people toward self-sufficiency and was tasked with encouraging this behavior from citizens.[28] This was a collective responsibility, to favor health in harmony with the overall environment, as well as an individual responsibility to be cultivated. The health system was well organized and public doctors were elected and paid for by the people.[29] However, there was also a social element to the doctor's intervention, in particular to provide a service to society. Although Hippocratic doctors cultivated their diagnostic skills, their prognostic skills were an important part of their craft, as they cemented the expertise of the physician.[30]

However, social opinions on physicians remained mixed: the word *pharmakos* after all means both remedy and poison.[31] Hippocratic medicine had few answers of the workings of the disease and the body. Physician's therapeutic action was mainly expectant while waiting and watching nature cure. Doctors occasionally provided a "helping hand"[32]; however, therapy was cautious: doctors largely preferred to prescribe dietetics (*dietetica*) rather than remedies. In Greek society, *dietetica* involved not only a healthy diet, but also

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[24] *Ibid.*, p. 39
[25] Tountas, Y. 2009. *The Historical Origins of the Basic Concepts of Health Promotion and Education: The Role of Ancient Greek Philosophy and Medicine.* Health Promotion International 24 (2), p. 187.
[26] *Ibid.* p. 187.
[27] *Ibid.*, Citing Sigerist's *History of Medicine* (1961)
[28] Tountas, Y. 2009. *The Historical Origins of the Basic Concepts of Health Promotion and Education: The Role of Ancient Greek Philosophy and Medicine.* Health Promotion International 24 (2), p 188.
[29] *Ibid.* p. 190.
[30] Porter, Roy. 1999. *The Greatest Benefit to Mankind: A Medical History of Humanity from Antiquity to the Present.* 1. paperback ed. London: Fontana Press. p. 61
[31] *Ibid.*, p. 4
[32] *Ibid.*, p. 59

athletic exercise and the well-regulated life encouraged by philosophers.[33] Historians in retrospect propose Greek medicine as patient-centered as it focused on dis-ease rather than diseases as ontological entities.[34]

Therefore, in this early formulation, we can already see several elements of patient empowerment present in our discussions today. First of all, we can see the responsibility of persons to both help themselves and their communities by favoring a healthy lifestyle. We can also witness the patient-centered approach advocated for by Hippocrates. Thirdly, we attest to the need for physicians to "prove" their value in society so that non-experts could both trust and benefit from this expertise. This model therefore mixed skepticism in medicine's abilities to heal with today's consumer model (in which the physicians need to prove their expertise), with an important role for the individual person to be self-sufficient.

The Romans: Self-help Methods

In the Roman era, Greek medicine—and doctors in general—were scorned. The Romans advocated instead for folk wisdom in the form of herbs and charms[35] and many relied on these and other "self-help" methods to cure themselves, helped along by texts such as Celsus' *On Medicine*. These self-help methods are partly a reflection of the organization of medicine in the Roman period, because competent and incompetent healers intermixed in large cities, making it difficult for citizens to assess expertise.[36] While the affluent could be treated in their homes, hospitals were built for the less fortunate and for soldiers. Therapies during this period however changed little from Greek times.

Galen, however, imposed his views during this era, influencing visions of the doctor's role. He advocated for a intertwining of philosophy and medicine: he thought that the physician must study logic, physics, and ethics to enable explanation and prognosis.[37] In Galen's conception, the person's trust in the physician was an important part of the healing process and medicine remained a personalized service to the sick. Under the Roman model, we can see a personalized healthcare plan provided to the individual. However, considerable skepticism in medicine's authority also encouraged self-help remedies.

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[33] *Ibid.*, p. 59
[34] *Ibid.*, p. 60
[35] *Ibid.*, p. 69
[36] *Ibid.*, p. 78
[37] *Ibid.*, p. 74

The Renaissance: Personalized Treatment Model

During the Middle Ages, historians say we cannot really talk of a patient-centered care model although we can see the beginnings of hospitality and a continuation of the importance of public hygiene in preventing disease.[38] During the Renaissance, however, the treatment model started to change, giving the possibility for a greater participation for the patient. While medicine made major advancements in anatomy, pharmacology, and surgery, these innovations did little to better the condition of the sick. According to medical historian Ray Porter, "*medicine during this time benefited more the doctor than the patient.*"[39] New learning hardly enabled the better treatment of diseases, but its organization through universities benefited the physician who gained a high social status.

Under this system, however, historians propose that the doctor-patient model can be proposed as "patient-centered," at least for the higher classes. For instance, in England of the 1700s, while physicians formed a small elite, and were considered gentlemen, they were considered less powerful and had fewer resources than the aristocratic patients they courted. This gave a certain power to the aristocratic patient, as doctors had to compete for business among this small class.[40] The illness model responded to this business model by paying attention to the patient's individual, singular symptoms. Thus, the relative status of physicians in society gave the means for patients to have—to a certain extent—the "upper hand," providing the means for a personalized healthcare plan.

The United States: More Self-help Models

If we move forward a few centuries (because the colonies were considerably behind Europe in medical knowledge), the germination of patient empowerment can be seen in what was to soon become the United States in the 18th century. During this time, skepticism in medial authority and the use of self-help methods were favored over the formal expertise of the doctor.[41] Physicians of the day were skeptical of medical practice and encouraged family medicine instead of physician-led medicine. Many even published

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[38] The Hebrews, for instance, despite eliminating a place for the physician or priestly healers in sacred texts, advocated for healthy cleanliness because it was associated with spiritual purity. Similarly, Christianity taught that it was the duty of the individual to look after his own body but also the community, expanding Jewish traditions of hospitality to care for the needy through the establishment of hospitals. *Ibid.*, p. 78

[39] *Ibid.*, p. 197

[40] Kaba, R., and P. Sooriakumaran. 2007. *The Evolution of the Doctor-Patient Relationship.* International Journal of Surgery 5 (1): 57–65.

[41] Starr, Paul. 2017. *The Social Transformation of American Medicine*. Updated edition. New York: Basic Books. p. 32

practical guides for households to enable them to do so. The best-known among these was William Buchan's *Domestic Medicine* (1769) showing preventive and curative strategies for households.[42] While Buchan himself was a member of the Royal College of Physicians in Edinburgh, he heavily criticized current medical practice and advocated that most people could heal themselves without professional knowledge and training.[43] This popular book became a best-seller of the day in the (soon to be) United States. These kinds of self-help books used both simple language and easy-to-reach household ingredients to care for the sick.

The idea that patients could "heal themselves" without the expert involvement of the physician had already been advocated before Buchan by non-physicians, such as John Wesley, the founder of Methodism. In his book *Primitive Physic* (1747), he chastised the medical profession for making its work "mystic" and compiled a list of popular remedies patients could use instead of visiting the physician.[44] Echoing our complaints of doctor's technical jargon today, he said, *"physicians now began to be had in admiration, as persons who were something more than human…and profit attended their employ as well as honor…so they now had two weighty reasons for keeping mankind at a distance, that they might not pry into the mysteries of the profession….they filled their writings with an abundance of technical terms, utterly intelligible…"*[45]

In the two systems we have highlighted, doctors had to prove their skill to have the business of patients, allowing patients to choose their doctors or even to choose to treat themselves. The mix of skepticism over medical authority, the possibility of layman healing themselves, and social attitudes emphasizing greater autonomy all encouraged an active participation for the patient, albeit at times excluding the doctor altogether.

The Rise of Modern Medicine and the Passive Patient?

As these historical examples highlight, self-help methods, mistrust in "expert" doctors, and individual and collective responsibility for individual health management are not only modern worries, they have been present throughout history. The idea of medical care being formulated, organized, and controlled by institutions—and "expert"

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[42] *Ibid.*, p. 32
[43] *Ibid.*, p. 33
[44] *Ibid.*, p. 33
[45] *Ibid.*, quoting John Wesley, *Primitive Physic: Or an Easy and Natural Method of Curing Most Diseases*. (1791).

physicians—is a relatively new concept in line with the collective organization of healthcare[46] as well as the rise of the biomedical vision of disease.[47] The institutional recognition of expertise (through the collective organization and recognition of healthcare workers) as well as a theoretical expertise (through the modern conception of biomedicine) consolidated a lesser role for the patient in both the institutional cadre and the collective imagination, at least for a time. Historian and doctor Le Fanu tell us why. He weaves a seductive tale of the "rise" of modern medicine. According to Le Fanu:

> *"The history of medicine in the fifty years since the end of the Second World War ranks as one of the most impressive epochs of human achievement. So dramatically successful has been the assault on disease that it is now almost impossible to imagine what life must have been like back in 1945, when death in childhood from polio, diphtheria and whooping cough were commonplace, when there were no drugs for tuberculosis, or schizophrenia, or rheumatoid arthritis, or indeed for virtually every disease the doctor encountered; a time before open-heart surgery, transplantation and test-tube babies. These, and a multitude of other developments, have been of immeasurable benefit, freeing people from the fear of illness and ultimately death, and significantly ameliorating the chronic disabilities of ageing."*[48]

These advances in healthcare highlighted by Le Fanu, which made impressive — and perhaps extraordinary — leaps and bounds changed the face of medicine, but also the doctor-patient relationship. By allowing doctors to be seen as epistemic authorities, it took away some of the self-help methods that we can see for patients throughout our historical narrative. From a historical viewpoint, the current promotion of patient empowerment is not out of place: as most of modern medicine's great innovations have been due to luck or trial and error the "ball was bound to drop" someday, bringing us back to a more nuanced view of modern medicine and its capacity to often treat — but not cure — us. Whether or not it was a mistake for medical authority to predominate over the patient's knowledge we cannot say. Historical hindsight judges too easily what was unclear during its time.

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[46] The decisive period for hospital organization was between 1800-1830 in France. It marked the break between illness theories and the advancement of modern clinical methods. These institutions made rapid progress in microbiology and surgery, transforming the illness model to the biomedical model of illness we know today. *Ibid.*, p. 54

[47] As this new model required an expert's examination of the body and extensive clinical and anatomical knowledge, the patient no longer had a strong role in the patient-doctor relationship. It was at this point, says Kaba and Sooriakumaran, that decisions about medical care was confined to the "experts." Kaba, R., and P. Sooriakumaran. 2007. *The Evolution of the Doctor-Patient Relationship.* International Journal of Surgery 5 (1): 57–65.

[48] Le Fanu, James. 2002. *The Rise and Fall of Modern Medicine*. 1st Carroll & Graf trade pbk. ed. New York: Carroll & Graf Publishers. p. XV

However, as we can now see that the dominance of a doctor's expertise is relatively new, we can also imagine a greater participation for the patient.

1.3. Philosophical and Social Movements

Let us now understand the germination of the recent patient empowerment movement. The purpose of this introductory investigation is to situate how patient empowerment emerged in the modern era. We will therefore investigate the overall context of the *empowerment* movement but also what specificities and issues come to light when putting the word patient *into* empowerment discourse.

Most scholars situate patient empowerment in the 20th century as part of wider political and social movements, reflecting society's call for greater autonomy and self-determination. In particular, they pinpoint existentialist philosophy and social discussions after World War II as the catalyst for our current preoccupations with citizens' roles, including in healthcare. We will also add to this contextualization our disappointment in modern medicine, as we will explain. While a useful framework to see empowerment as a relatively "new" discussion, tied to these political and social movements, we have already shown that patient participation in healthcare decision making is not new. We will now proceed by situating empowerment discussions in wider social and philosophical ideas in order to help us understand how and why patient empowerment is being promoted today.

Most introductions in international scholarly literature[49] about patient empowerment pinpoint patient empowerment's origin in civil rights movements from the 1960s as well as the rise of bioethics. However, before understanding these underpinnings, we will need to understand more fully the philosophical ideas that made these movements possible in order to highlight the contradictions and difficulties of patient empowerment as a directive for public policy.

[49] In this chapter, we are largely relying on references from international journals in English; this is because the majority of conceptual debate over patient empowerment largely takes place in these forums. In addition, the debate is taking place both in local infrastructures and in international forums, including academia but also in research organizations, pharmaceutical companies, national and international political forums, etc. We have however highlighted several political movements in specific countries (see the section on the politics of the New Rights movements in the UK and the US), because of their influence on other healthcare infrastructures. However see Chapter 3 to understand how the specificity of the French healthcare system has been able to provide the patient life empowerment approach we advocate.

Freedom, the Individual, and Identity

It was during the 17th century that the word *empower* emerged for the first time in Great Britain. To *empower* in its etymology means a higher power *accords* power to someone less powerful (em-power).[50] Therefore, to empower means 1) giving power or authority and 2) giving ability to or permitting.[51] In this first formulation, we can understand that freedom was granted as a *privilege* to a person or a group by the master. Empowerment was conceived in the context of a society organized for control of a master over man.

This social organization, however, started to change from the 17th and 18th centuries, when freedom became separated from the jurisdiction of the land estate.[52] These changes were in turn the impetus for new ideas on freedom, the individual, and identity.[53] In the new urban social order that resulted from these changes, mankind was conceptualized in a new way, as dictated by human reason. With this new vision of the individual and critical self-awareness, the distinction between oneself and the other started to enter social consciousness.[54] In turn, conceptualizations of identity starting from the European Enlightenment led to new assertions of autonomy. Marxist philosophy further conceptualized this emancipation, by seeking liberation from those who owned the means of production through awakening of critical class consciousness. It was in the middle of the 19th century the word "empowerment" was formed, designating both a state and an action and thus (at least partly) departing from its original etymology.[55]

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[50] Bacqué, M.-H., Biewener, C., 2013. *L'empowerment, un nouveau vocabulaire pour parler de participation ?* Idées économiques et sociales 173, p. 25.
[51] Staples, Lee H. 1990. *Powerful Ideas About Empowerment.* Administration in Social Work 14 (2): 29–42. p. 29.
[52] Traynor, M., 2003. *A brief history of empowerment: response to discussion with Julianne Cheek*. Primary Health Care Research and Development 4, p. 130.
[53] *Ibid.*, p. 130.
[54] Traynor highlights Aristotle's understanding of the polis, which starts from the collective; while thinkers such as Hobbes start their conceptualisations of the social order from a society of prosocial individuals and how they can make compromises to form a state. *Ibid.*, p. 131.
[55] Bacqué, M.-H., Biewener, C., 2013. *L'empowerment, un nouveau vocabulaire pour parler de participation ?* Idées économiques et sociales 173, p. 25.

Patient Empowerment within Civil Rights Movements

Following World War II, these ideas, as well as new movements in psychology[56], helped to catalyze the empowerment movement. The period's moral questioning of why some people were able to achieve more independence than others, in a world grappling with why some resisted and others collaborated, became a flashpoint for psychological, political, philosophical, and social discussions on autonomy and self-determination.[57] From the 1960s and 1970s, these calls for greater autonomy and self-determination crystallized into the civil rights movement. The empowerment movement has been one of the outcomes and is tied to a variety of influences, such as feminism, the Black Power movement, and Paolo Freire's work on popular education[58]; however, only from 1975 and Barbara Solomon's work on *Black Empowerment: Social Work in Oppressed Communities*[59] was the term used by social services and researchers.[60]

In her book, Solomon offers empowerment as a goal for social work, which she defines as, *"a process whereby the social worker engages in a set of activities with the client or client system that aims to reduce the powerlessness that has been created by negative valuations based on membership in a stigmatized group."*[61] In this first formulation of empowerment following the civil rights movement, we have not fully moved beyond the first etymology of *em-power*. However the one giving power, in this case social workers, would no longer see it as a privilege to be accorded, but as an ethical and political project to be defended for the benefit of others.

A pertinent aspect of Solomon's proposal of empowerment is her definition of *powerlessness*, which takes into account the resources and how the social environment affects the person's perception of these resources. She defines powerlessness as, "*the inability to manage emotions, skills, knowledge, and/or material resources in a way that effective performance of valued social roles will lead to personal gratification."*[62] In

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[56] O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press. p. 23

[57] One famous example was the Milgram experiments, which were designed to measure an individual's conformism/collusion with authority figures, *Ibid.*, p. 23-24

[58] Freire, Paulo. 2000. *Pedagogy of the Oppressed*. 30th anniversary ed. New York: Continuum

[59] Solomon, B.B., 1976. *Black empowerment: social work in oppressed communities*. Columbia University Press, New York.

[60] Calvès, Anne-Emmanuèle. 2009. *« Empowerment » : généalogie d'un concept clé du discours contemporain sur le développement.* Revue Tiers Monde 200 (4): 735.

[61] Solomon, B.B., 1976. *Black empowerment: social work in oppressed communities*. Columbia University Press, New York. p. 19.

[62] Carr quoting Solomon, *Ibid.*, p. 16, E.S., 2003. *Rethinking Empowerment Theory Using a Feminist Lens: The Importance of Process*. Affilia 18, p. 13.

Solomon's view, powerlessness is more complicated than just lacking power; people are also prevented from acting by self-perceptions about their resources.[63] Empowerment for Solomon is thus about overcoming powerlessness both *felt* and *enacted* through support provision.

Since Solomon's book, empowerment has grown to be seen as both an individual and collective activity. The person credited with adding this collective aspect to the empowerment definition is Paolo Freire and his work on popular education.[64] His book is often now cited as *the* reference for the empowerment movement. Drawing heavily from Marxist philosophy, Freire advocates moving from a *dominated consciousness* to a *critical consciousness* in order to overcome political oppression.[65] For Freire, *critical consciousness* is a group process in which individuals collectively identify the common roots of their own powerlessness in order to be able to act as a group to overcome their oppression. In Freire's view, the key point in the process is for individuals to become aware of themselves as subjects, a process that he calls *conscientization.* Due to this focus on *conscientization*, many empowerment definitions and policy directions have drawn insights from development psychology. The focus of these directions becomes helping unempowered persons to develop the skills, understandings, and resources to be empowered. The process is often viewed as linear and when it is achieved, a result.[66]

There are several limitations, however, of conceptualizing empowerment in this way. In the first place, understanding patient empowerment through the lens of development psychology makes it seem like a process stemming from individual beliefs and behaviors, thus putting the responsibility on the individual, rather than investigating the environment in which a person can or cannot act. Barbara Solomon's idea of powerlessness understood the critical dimension of the environment. Similarly, feminist scholars have heavily criticized empowerment's lack of focus on the structural conditions in which empowerment occurs. Carr for example declaims that *"empowerment seems to exist in a vacuum in that contextual and structural factors are noted but not integrated into this developmental paradigm.*"[67]

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[63] This is similar to what capability scholars would call "adapted preferences." See Chapter 3.
[64] Freire, Paulo. 2000. *Pedagogy of the Oppressed*. 30th anniversary ed. New York: Continuum
[65] *Ibid.*, p. 36.
[66] Carr, E.S., 2003. *Rethinking Empowerment Theory Using a Feminist Lens: The Importance of Process*. Affilia 18, p. 9.
[67] Carr argues for seeing empowerment not as a linear process but as one that is mutually reinforcing and inter-connecting, with several sub-processes. *Ibid.*, p.13.

This understanding of the critical role of the environment has not been integrated into most patient empowerment conceptualizations and programming, as we will soon see. Putting all responsibility on the patient to "manage" her health behaviors is not only unrealistic, but it also does not move us beyond the paternalistic models that empowerment movements are seeking to achieve. The patient life empowerment approach we propose will incorporate the influence of the environment.

Another problem comes from viewing empowerment as a linear process: we may give tools to practitioners to empower those are "unempowered" (thus helping us see the relational role of stimulating empowerment) but it also means that practitioners are the ones who will decide how and in what way empowerment has been achieved. We will see just how pervasive these two problems are in patient empowerment discussions and formulations and why we need approaches coming from the patient throughout this chapter.

Changing Healthcare Practices and Patient Empowerment

We have outlined philosophical and social changes that helped the empowerment movement emerge. At the same period as these overall social movements, changes were also happening in the healthcare field that would have an impact on patient empowerment and its promotion in healthcare institutions. Notably during this time, bioethics as a discipline (or at least using the term as a meeting point of multidisciplinary debate) was also coming into being. In healthcare this lead to advocacy for the right to informed consent (following the Nuremburg trials, drafted in the 1960s), the rights of the mentally ill, and calls for patients' right to participate in their healthcare,[68] especially in light of healthcare scandals.[69] Patients' rights became a priority in these debates.

In public health discussions on a wider scale, patient empowerment discussions in the 1970s were also influenced by international charters that have sought to put health promotion on the global agenda as a "human right." The first among these was the Alma-Alta Charter in 1978. The charter affirmed that,

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[68] Steele, David J., Barry Blackwell, Mary C. Gutmann, and Thomas C. Jackson. 1987. *Beyond Advocacy: A Review of the Active Patient Concept.* Patient Education and Counseling 10 (1): 3–23. p. 6.

[69] Mougeot, F., Robelet, M., Rambaud, C., Occelli, P., Buchet-Poyau, K., Touzet, S., Michel, P., 2018. *L'émergence du patient-acteur dans la sécurité des soins en France : une revue narrative de la littérature entre sciences sociales et santé publique.* Santé Publique 30, p. 75.

> *"The Conference strongly reaffirms that health, which is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, is a fundamental* ***human right***[70] *and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector."*[71]

While the Alma-Alta declaration has been heavily criticized for failing to achieve its potential, seeing empowerment from the human rights angle has widened the discussions about patient empowerment toward a systematic, even global view of health, with many responsible actors (thus reinforcing its collective aspect). The human rights perspective has helped move perceptions of the patient beyond the standpoint of individual autonomy by focusing on structural barriers that require action on multiple levels.[72] However, as we shall see, the idea of individual autonomy returned to patient empowerment definitions and remains pervasive in these definitions.

In addition to seeing health as a human right, an equally important movement during this period was the advocacy for social change in medical practice coming from healthcare professionals themselves. As nurses and other paramedical professionals claimed their right to participation in medical decision-making along with doctors, they in turn demanded new programs to facilitate greater patient interaction.[73]

We can therefore identify multiple factors influencing the development of patient empowerment, including wider social discourses calling for greater social participation, calls for greater autonomy in decision-making, and in the case of healthcare professionals, for greater recognition of their role in care provision. While empowerment discussions are said to have evolved in order to increase citizens' rights to participate, they have also been transformed through these diverse groups and interests. In particular, given healthcare providers' influence in promotion of the patient empowerment movement to change their own working conditions, we will need to be mindful of whose interests it represents when formulated into programming in healthcare institutions.

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[70] Emphasis added.

[71] Quoting the Declaration of Alma-Ata, International Conference on Primary Health Care, Alma-Ata, USSR, September 6–12, 1978. World Health Organization. In Birn, Anne-Emanuelle. 2018. *Back to Alma-Ata, From 1978 to 2018 and Beyond.* American Journal of Public Health 108 (9): 1153–55.

[72] Pulvirenti, Mariastella, John McMillan, and Sharon Lawn. 2014. *Empowerment, Patient Centred Care and Self-Management. Health Expectations* 17 (3): 303–10. p. 309.

[73] Steele, David J., Barry Blackwell, Mary C. Gutmann, and Thomas C. Jackson. 1987. *Beyond Advocacy: A Review of the Active Patient Concept. Patient Education and Counseling* 10 (1): 3–23. p. 6.

Modern Medicine's Fall

We will add two more elements to the rise of the patient empowerment movement in (mainly) Western societies today. The first element follows Le Fanu's analysis of the "fall" of modern medicine. Le Fanu, as both a doctor and a historian, claims that we started to lose our trust in modern medicine at about the same period as increasing calls for patient participation in civil rights movements. He identifies the 1970s as the "hard fall" of modern medicine[74] for failing to elucidate the cause of disease.[75] According to Le Fanu,

> *"The main causes of common disease are neither genetic nor social, but rather are either age-determined or biological and (for the most part) unknown…medicine's post-war success, built on the chance discovery of drugs and technological innovation, concealed the fact that its impressive achievement has been won without the necessity to understand the nature or causation of disease."*[76]

For Le Fanu, the great unknown of the nature and causation of disease has led to many strategies: pharmaceutical companies who keep hammering away to provide more and more variants of drugs, even if not necessarily more therapeutically effective; medicine trying to get around treatments with more and more complex and expensive (and at times unnecessary) strategies; and the social theory of disease that tried to prevent disease in the first place (leading to the so-called "worried well"). According to him, these processes, rather than casting doubt on modern medicine, has "*sustained, even enhanced, its dominant position within Western society. Medicine has never been so powerful, and yet its success is seriously compromised by…the four-fold paradox (disillusioned doctors, the worried well, the spiraling costs of healthcare, and the increasing popularity of alternative medicines)."*[77] In addition to the factors emphasized by Le Fanu, we can add the increasing complexity of technological and pharmaceutical healthcare plans, putting additional difficulties on disease treatment for both doctors and patients, and the increasing strains of rousing public support for funds dedicated to patient care and to disease research.

However, in spite of all of these changes, transformations, and reconfigurations, the doctor-patient relationship has remained the fundamental human bedrock of the healthcare relationship. Moreover, within it the doctor's role remains largely the same (to do no harm,

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[74] Le Fanu, James. 2002. *The Rise and Fall of Modern Medicine*. 1st Carroll & Graf trade pbk. ed. New York: Carroll & Graf Publishers. p. 239
[75] *Ibid.*, p. 339
[76] *Ibid.*, p. 340
[77] *Ibid.*, p. 357-358

to cure and to treat to the best of her ability). However, the patient now seems to be asking for a larger role, but the question remains, a larger role in what?

Empowerment and the New Right: Uneasy Bedfellows

Concurrently with empowerment movements and disappoint in modern medicine is yet another shifting social influence: the rise of powerful political movements such as New Right politics in the United States and the United Kingdom.[78] These political groups have influenced the rise and formulation of the patient empowerment movement as a whole, not only in these countries. Traynor calls them patient empowerment's "uneasy bedfellows."[79] Because these policies encourage a minimalist vision of the state, patients have been encouraged to become "consumers/customers" rather than "passive recipients" of professional expertise. These ideologies have influenced what is often viewed as citizen or social movements such as the self-help movement in the 1980s, advocating for autonomous health management and disease prevention and advocacy to change healthcare vocabulary.[80]

Although these ideas have helped move patients from being seen as *passive* to *active*, it has also led to high expectations of the individual's abilities to manage their healthcare. In this chapter we will investigate whether these policies have actually reduced the power of professionals, or if we are putting unrealistic — and unfeasible — expectations on patients in an environment in which they cannot realistically act.

Foucault argued that biopower in public health has reinforced hierarchies and population segregation, leading to surveillance that is penetrating deeper and deeper into individual and family spheres.[81] Individual health "management" as advocated for by these political movements has several competing aims. On the one hand, there is the promotion of the individual's rights, helped along by concepts of autonomy and humanitarian principles. Concurrently, capitalist priorities come into play by advocating for a healthy workforce and cost reduction. As healthcare is turning from acute to chronic care, requiring the active involvement of the patient (and the family) due to long-term treatment

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[78] Traynor, M., 2003. *A brief history of empowerment: response to discussion with Julianne Cheek*. Primary Health Care Research and Development 4, p. 133.
[79] *Ibid.*, p. 133.
[80] In the English language, at least, doctors from the 1980s started to be called "healthcare service providers" and patients "users" or even "consumers," emphasizing the service component to healthcare. Steele, David J., Barry Blackwell, Mary C. Gutmann, and Thomas C. Jackson. 1987. *Beyond Advocacy: A Review of the Active Patient Concept. Patient Education and Counseling* 10 (1): 3–23. p. 5.
[81] Foucault, M., 1997. *La volonté de savoir, Histoire de la sexualité.* Gallimard, Paris. p. 64.

regimes, and requiring compliance to see whether treatments are working, patient empowerment discussions have aligned with public policy and biomedical goals.[82] We will need to question whether or not the patient's participation has therefore really increased or whether we are still stuck in a model where "the doctor knows best."

The "call" for patient empowerment has therefore come from both within and outside of the healthcare system, responding to citizens' calls for participation but also social needs. Under these competing interests, patient's individual ideas of empowerment easily are manipulated for political gains. Traynor expresses this as,

> *"Empowerment' is in danger of placing such emphasis on personal responsibility that it can perpetuate the status quo by failing to give attention to massive, but taken-for-granted, structural constraints on the life and consciousness of the individual. 'Empowerment' in the hands of state professionals can involve a manipulation of the consciousness of the individual into believing that their own health status is largely a result of conscious decisions and individual behaviors rather than less visible, but none the less effective structural forces. So, ironically, 'empowerment' can perpetuate ideology. After all, this is what the most effective ideology does—it tells the individual subject that he or she is free while at the same time constructing the possibilities for thought and action."*[83]

These diverse movements have led to an assumption that the patient wishes to participate in an active way in their healthcare; however, healthcare providers and their institutions have largely dictated their ways and means of participation, as we will see. What does participation in an active way involve? Does it merely involve following the treatment plan as prescribed? Alternatively, does it encompass a wider scope of responsibility, such as finding ways and means to complement – or replace – the doctor's expertise? Furthermore, are we mainly interested in health "management" from a biomedical perspective, such as adherence, or are we incorporating experiential knowledge developed by the patient? Finally, who is involved in this participation: are we only talking about the patient, or can we also imagine a role for family members or even society?

Given the diverse interests inherent in this discussion, we need to be mindful of these assumptions in order to develop an approach stemming from the patient. To unravel this difficulty, we first need to ask if patients even want to participate "actively" in their

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[82] Traynor, M., 2003. *A brief history of empowerment: response to discussion with Julianne Cheek*. Primary Health Care Research and Development 4, p. 134-135.
[83] *Ibid.*, p. 135.

healthcare. And if so, what does participation mean to them? In other words, how do patients envisage their participation both inside and outside the consultation room? And what result are they looking for through their participation? In order for healthcare to actually empower patients, rather than *em-power* them to act in certain ways, we will need new vocabularies and new methodologies to demarcate what the patient is looking for from their healthcare. This is the ambition of this thesis.

1.4. Patient Empowerment Definitions

Having understood the diverse political and social movements, as well as historical moments when a greater role for the patient has emerged, let us now move to current definitions of patient empowerment. In the first place, it must be said that there exists no consensus. While patient groups and research scholars have proposed a variety of definitions, they are not used with any consistency.[84] As patient empowerment is a "hot" topic in public policy discussions, patient associations, as well as among healthcare providers, definitions of patient empowerment continue to vary widely depending on the context and interest group in which it is used. We will now see how these various definitions have aligned with some of the problems we have been discussing.

Among popular definitions are:

[1] An educational process designed to help patients develop the knowledge, skills, attitudes and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions[85]

[2] A redistribution of power between patients and physicians. Empowered patients attempt to take charge of their health and their interactions with healthcare professionals.[86]

[3] A process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important."[87]

The first definition proposed, "*an educational process designed to help patients develop the knowledge, skills, attitudes and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions,"* is problematic. In the first place, empowerment is seen a linear process, and even more, now it has been defined as an "educational process," which necessarily means there will be an educator (the doctor?) and the person to be educated (the patient?). Here it is clear that the educator will

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[84] Roberts, Kathleen Johnston. 1999. *Patient Empowerment in the United States: A Critical Commentary.* Health Expectations 2 (2). p. 90.

[85] Feste, Catherine, and Robert M. Anderson. 1995. *Empowerment: From Philosophy to Practice.* Patient Education and Counseling 26 (1–3). p. 140.

[86] Roberts, Kathleen Johnston. 1999. *Patient Empowerment in the United States: A Critical Commentary.* Health Expectations 2 (2). p. 82.

[87] European Patients Forum definition. "Patient Empowerment." n.d. Accessed February 21, 2019. http://www.eu-patient.eu/whatwedo/Policy/patient-empowerment/.

be the one to decide what *knowledge, skills, attitudes, and degree of self-awareness* will be developed in order to decide whether the patient can assume responsibility for health-related decisions. This definition is clearly orientated toward public heath's priorities by seeing empowerment as a way to encourage individual patient responsibility.

The second definition, "*a redistribution of power between patients and physicians. Empowered patients attempt to take charge of their health and their interactions with healthcare professionals,"* takes into focus the collective empowerment movement, seeing it as part of a general social trend involving the redistribution of power. The author clearly seeks to mark patient empowerment as an outcome in which power inequalities have either been reduced or eliminated. However, the definition then goes on to show that empowered patients "take charge" of their health. Here we are again advocating for patient autonomy as a means to impose individual responsibility. However, an interesting aspect of this definition is its relational aspect: we see patients in a relationship, one that involves an equal or a re-distributive relationship involving patient participation.

The third definition is, "a *process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important*." This is the most promising formulation of patient empowerment for our use. Here we can clearly see that it is the patient's right to act and to define what is important for them in their lives. In addition, although viewed as a process (linear?), the focus here is for patients to gain control[88] of their lives, not just in their medical care. However a limitation of this definition is that it does not take into account the structural conditions in which patient empowerment happens on the ground.

In these definitions, the responsibility for patient empowerment has varied depending on its focus on the individual patient level, the doctor-patient relationship, or on the healthcare system or society level. Depending on what level is promoted, patient empowerment leads to different interpretations (such as a theory, a process, an intervention, an outcome)[89] and to different policies and programming priorities.[90] The

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[88] This idea of taking control is also present in the idea of health promotion in the Ottawa Charter, which says that, "*people cannot achieve their fullest health potential unless they are able to take control of those things which determine their health."* World Health Organization, 1986. *Ottawa Charter for Health Promotion*. We will return to the idea of "taking control" from the patient's perspective in Chapter 3.

[89] Castro, Eva Marie, Tine Van Regenmortel, Kris Vanhaecht, Walter Sermeus, and Ann Van Hecke. 2016. *Patient Empowerment, Patient Participation and Patient-Centeredness in Hospital Care: A Concept Analysis Based on a Literature Review.* Patient Education and Counseling 99 (12): 1923–39. p. 3.

[90] Because it is seen as a process/outcome, a variety of measures has sought to evaluate patient empowerment. We will discuss one of these (the patient activation measure) at the end of this chapter.

issue of who is responsible for facilitating and deciding the content of patient empowerment programming will be an important theme to explore in this thesis. These varying definitions of responsibility have led to a number of difficulties for the design and implementation of patient empowerment on the ground. For instance, who is responsible for the process of patient empowerment: the doctor, the patient, the family, or society? Should we focus on patient empowerment in the doctor-patient relationship or encourage a vision of the patient in overall life in society? Should we focus on patient empowerment as a process or as an outcome, or both? Making this choice will influence what we mean by knowledge, skills, and attitudes necessary to assume responsibility and the persons responsible for deciding how these outcomes have been achieved. Thus a practical question to ask will be if in our institutions we should we focus on the patient (facilitating greater individual autonomy, both inside and outside of the doctor's office) or whether we should focus on improving relationships with healthcare providers (encouraging the relational component in healthcare).

The multitude of definitions, conceptions, as well as interests has led to confusion for healthcare institutions, policy makers, patient associations, and especially for patients and families themselves. According to Roberts, *"the lack of theoretical guidance and simplification of the concept call for the need for more qualitative research. Such research could elicit individuals' own definitions of patient empowerment, which would, in turn facilitate the development of better theoretical models of the concept."*[91] This thesis proposes to introduce the patient's view of empowerment (Chapters 2 and 3) based upon qualitative research conducted in France and China. However, in order to prepare this discussion, in this chapter will be exploring some of the definitions proposed and their problems. A few of these problems include:

McAllister *et al*. advocate for patient-reported outcomes to be input into questionnaires/evaluations in order to allow patient reported outcomes to be prioritised. They argue in particular for this type of outcome as patients may value empowerment as an outcome even if it is not related to their health status. This idea aligns with our project, although we do not seek to propose an evaluation measure for healthcare institutions at this time as this research was a preliminary exploration of what could be patient empowerment from the patient's perspective. For a discussion on these various instruments, see: McAllister, M., Dunn, G., Payne, K., Davies, L., Todd, C., 2012. *Patient empowerment: The need to consider it as a measurable patient-reported outcome for chronic conditions.* BMC Health Serv Res 12, 157.

[91] Roberts, Kathleen Johnston. 1999. *Patient Empowerment in the United States: A Critical Commentary.* Health Expectations 2 (2): 82–92. p. 82.

- The different conceptions of patient empowerment for patients and healthcare providers
- The different priorities of patient empowerment among healthcare institutions, patient associations, political and economic actors
- A discussion of what should be prioritized in patient empowerment: the overall patient environment or the patient-doctor relationship
- If patient empowerment comes from the bottom or the top and what this implies for the patient's participation
- What the differing conceptions of patient empowerment mean for the patient's rights and responsibilities

In order to proceed with our discussion, we will use Robert's preliminary idea of patient empowerment as a*, "vision of a patient moving from passive to active in their health management, including in their interactions with healthcare professionals*."[92] This will allow us to investigate whether or not the doctor-patient relationship is the key relationship that needs to be highlighted, or whether a more holistic, social perspective is necessary. It will also allow us to understand whether or not patients have moved from a "passive" to an "active" state and what that actually means.

The Predominance of the Doctor-Patient Relationship

In the first place, the idea that patients have become active comes as we have seen, from social movements that advocate for persons to be seen as a "subject" with power and capacities to act. By focusing on "action," patient empowerment has become a process or an outcome whereby patients "gain control" of their lives, including in the healthcare relationship. Therefore, a key relationship that has changed (highlighted in Robert's definition as well as in other definitions of patient empowerment) is the doctor-patient relationship. Patient empowerment is said to occur when patients leave the *sick role*[93] to become more involved or "active" in their relations with the doctor. However, what is this role, to what extent the patient can act "autonomously" in the doctor-patient relationship, and how "autonomously" in return the doctor can act, has not been adequately explored.

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[92] *Ibid.*
[93] Parsons, Talcott. 1968. *The Social System*. Free Press. p. 285

Foucault famously argued that power over the body since the 17th century has evolved into two forms of control: the control of the body as a machine (including its integration into systems of efficient and economic controls), and a biopolitics of the biological process, seeking to control the body through regulations.[94] For Foucault, biopower relates to the practice of modern nation states which use numerous and diverse techniques to control bodies and populations.[95] This includes regulating the birth rate, longevity, public health, habitat, etc. According to him, biopower was essential to capitalism, giving the means to measure and intervene into the body. For Foucault, capitalism would not have been possible without the control of bodies in the machinery of production and the adjustment of the population to economic processes.[96] Therefore is patient empowerment a means to "give capacity" to the patient to find their own ways and means to manage their life with disease? Or on the contrary, paying attention to Foucault's warning, are we merely seeking another means of control of the body in order to ensure measures such as a healthy workforce or to decrease costs? In the next section (biomedical claims), we will need to see in what measure the patient effectively has agency in this "new" formulation or whether that agency is illusory as it merely involves following the doctor's orders once outside of the consultation room.

The Question of Autonomy

Before continuing this discussion, let us question whether autonomy could be a good criterion for a definition of patient empowerment. Since the beginning of bioethics discussions in the 1970s, no theme has been as central and ongoing as the respect for individual rights and autonomy.[97] In medical ethics, much scholarly attention has gone into formulating and justifying various conceptions and ways of ensuring this ideal.[98] The principle of respect for autonomy has usually meant giving decision-making power to patients in healthcare decisions; however, in chronic disease conditions, this principle has expanded to include behaviors outside the consultation room in daily disease

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[94] Foucault, M., 1997. *La volonté de savoir, Histoire de la sexualité.* Gallimard, Paris. p. 183. See also: Foucault, M., Ewald, F., Fontana, A., Senellart, M., 2004. *Naissance de la biopolitique: cours au Collège de France, 1978-1979*, Hautes études. Gallimard : Seuil, Paris.
[95] Foucault, M., 1997. *La volonté de savoir, Histoire de la sexualité*. Gallimard, Paris. p. 184.
[96] *Ibid.* p.184-185.
[97] O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press. p.2
[98] *Ibid.*, p. 2

management.[99] These discussions have also found their way into patient empowerment discussions. Feste *et al*. say for instance that, *"the empowerment approach to health education seeks to increase patient autonomy and expands freedom of choice. Health education is carried out to prepare people to function effectively as equal and autonomous members of the healthcare team."*[100] Is autonomy a useful theoretical framework from which to base patient empowerment? Is patient autonomy defined by overall bioethics discussions used in the same way as in patient empowerment discussions? And especially, what are we talking about here: the patient's rights or the patient's responsibilities?

Respect for autonomy is now viewed not only as a standard in healthcare, but an obligation,[101] although we still do not seem to have a firm epistemic hold on what exactly autonomy means in the healthcare field.[102] However, as Dworkin famously phrased it, what seems apparent is that autonomy is seen as "important" to persons and, as a "desirable" quality to be cultivated.[103] If we can accept these two premises, we will need to identify in what ways and means autonomy is "important" (i.e. who is it important to?) and if it is "desirable," we should look at how it can be cultivated or encouraged on the ground.

For our purposes, we will use Beauchamp and Childress' fairly inclusive and ambitious definition of autonomy, especially because much discussion has been centered over their formulation of autonomy in the healthcare context. These scholars underline two essential conditions for autonomy: (1) liberty (independence from controlling influences) and (2) agency (capacity for intentional action).[104] They further elaborate on these two

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[99] Enzo, Aya, Taketoshi Okita, and Atsushi Asai. 2019. *What Deserves Our Respect? Reexamination of Respect for Autonomy in the Context of the Management of Chronic Conditions.* Medicine, Health Care and Philosophy 22 (1): 85–94. p. 85

[100] Feste, Catherine, and Robert M. Anderson. 1995. *Empowerment: From Philosophy to Practice.* Patient Education and Counseling 26 (1–3). p. 140.

[101] O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press. p. 2

[102] Dworkin famously said, "*It is apparent that, although not used just as a synonym for qualities that are usually approved of, 'autonomy" is used in an extremely broad fashion. It is used sometimes as an equivalent of liberty…sometimes as equivalent to self-rule or sovereignty, sometimes as identification with freedom of the will. It is equated with dignity, with integrity, individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one's own interests…it is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts, and to principles. About the only features held constant from one authority to another are that autonomy is a feature of persons and that it is a desirable quality to have."* Dworkin, Gerald. 1988. *The Theory and Practice of Autonomy*. Cambridge Studies in Philosophy. Cambridge ; New York: Cambridge University Press. p. 6

[103] Based on Dworkin's definition, the footnote above.

[104] Beauchamp, Tom L., and James F. Childress. 2001. *Principles of Biomedical Ethics.* 5th ed. New York, N.Y: Oxford University Press. p. 58

criteria in their 5th edition of the *Principles of Biomedical Ethics* to specify autonomous action in terms of choosers who act (1) intentionally[105] (2) with understanding (3) without controlling influences that determine their action.[106] However, their definition also recognizes the relational factor to reach of these conditions, which is to say that choosers act to a greater or lesser extent depending on their own capacities as well as the environment supporting them. Recognizing both the capacities of the person and their environment, they require a minimum standard to enable autonomous decisions (which can be more or less autonomous depending on the person and whether they can and wish to be autonomous). They say that,

> *"To respect an autonomous agent is, at a minimum, to acknowledge that person's right to hold views, to make choices, and to take actions based on personal values and beliefs. Such respect involves respectful action, not merely a respectful attitude. It requires more than non-interference in other's personal affairs. It includes, at least in some contexts, obligations to build up or maintain others' capacities for autonomous choice while helping to allay fears and other conditions that destroy or disrupt their autonomous actions.*"[107]

Looked at from this holistic framework, autonomy gives rights to patients (and acknowledges their ability to make choices based upon their values) but it also imposes obligations on healthcare providers (to build up or maintain patients' capacities for choice, including by helping prevent or ease factors which might destroy or disrupt autonomous actions). In this formulation of autonomy, both individual rights (to choose) are recognized but also the role of others to ensure these rights are actually feasible. If we apply this formulation to patient empowerment, we are asking (in a minimalist formulation) that patients be allowed to make their own healthcare choices based upon their values, and that doctors should respect, support, and even help to develop their possibilities to make choices. Therefore, healthcare professionals play a key role in providing a facilitating — or inhibiting — patients' capacity to exercise their choices.

Under these formulations, however, it is often understood that a minimum threshold of competency applies.[108] There are, of course, many criticisms[109] and alternative proposals

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[105] Here they specify that actions are either *"intentional or nonintentional; however, acts can satisfy both the condition of understanding and absence of controlling influences to different degrees." Ibid.*, p. 59
[106] *Ibid.*, p. 59
[107] *Ibid.*, p. 63
[108] Dodds, Susan. *Choice and Control in Feminist Bioethics.* In Mackenzie, Catriona, and Natalie Stoljar, eds. 2000. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press. p. 214.
[109] Due to the varying shades/degrees/temporalities of competency, etc.

to this idea; for our subject, the problem is that it gives the doctor considerable decision-making power over the patient. Even more problematic for our purposes is that autonomy in the doctor-patient relationship has been instrumentalized on the ground into informed consent. As O'Neill tells us, by choosing informed consent as the means to exert autonomy in the doctor-patient relationship, we may make it possible for individuals to choose autonomously, but we cannot guarantee (or even require) this.[110] Or in other words, to return to Beauchamp and Childress' model, if the patient's role consists only in informed consent, then it is muddy at best to understand how patients can act intentionally (unless the intention is in line with the doctor's authority) even if the patient may be able to act with understanding (information from the doctor and from themselves).

To add a further difficulty, Dodds points out that "autonomy" and "capacity for choice" is not the same thing.[111] She says that most healthcare choices are limited choices, influenced by the healthcare infrastructure in place (what can be offered to the patient), but also motivated by the information that doctors think is useful and relevant to help the patient make that choice.[112] For instance, if doctors believe in the nocebo effect, they may deem giving information on side effects harmful, whereas if the patient was fully informed, they might not make the same choice. This shows us a limited capacity for autonomous choice for patients in deciding their healthcare plan.

In addition, the means by which doctors can provide a capacity for choice and patients can and will use it, has hit a number of practical roadblocks. As we will see in the next section, it is at times difficult for patients (at certain temporalities of the patient-doctor encounter) to exercise choice given the different goals of the patient and the doctor. In addition, it cannot be said that patients do not act without controlling influences that determine their action, as patients rely on the doctor's authority, but also on their families, their friends, and society's views when they decide to accept and adhere to treatment.

What this shows us is a reality: in the doctor-patient relationship, neither full autonomy nor full capacity for choice is possible. Is this a problem for patients? We will need to solicit patient's understandings of autonomy and to ask patients directly how they

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[110] O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press. p. 37

[111] Dodds, Susan. *Choice and Control in Feminist Bioethics.* In Mackenzie, Catriona, and Natalie Stoljar, eds. 2000. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press. p. 215

[112] *Ibid.*

desire to be empowered in the healthcare relationship, in order to understand this issue from the patient's perspective.

We have now established that autonomy in the doctor-patient relationship is not fully possible. However, for our uses, we are also interested in the autonomous role for patients when they are outside of the clinical setting. To return to Beauchamp and Childress's formulation, patients are "autonomous agents" outside of the consultation room, with the right to act as they wish, based upon their "personal values and beliefs." The doctor's role is therefore in "respectful action," encouraging patients to find ways to be empowered outside of the doctor-patient relationship (when patients decide to share or ask advice), but it largely involves "non-interfering" in their personal domain as patients are "autonomous agents" once outside the doctor's office. In essence, the doctor's reign of legitimacy to influence the patient's behaviors outside of the consultation room is over as they are now in their personal domain. However, as we will see in the next section on biomedical claims, current definitions of patient empowerment impose certain obligations outside of the clinical setting, thereby not aligning with Beauchamp and Childress' call for respectful action.

Relational Autonomy

Given the insufficiency of the autonomy concept in healthcare, the literature on this subject is extensive, and to a certain extent, non-ending. While many researchers object to the formulation of individual autonomy, we are still grappling to find a better solution. Many reformulations have been proposed. Some are inspired from the Kantian perspective of "seeing each person as an end" with diverse proposals such as principled autonomy[113], or modifying individual autonomy with reformulations of old terms such as "respect for persons."[114] There have also been proposals to demarcate the various levels of autonomy to

[113] O'Neill defines principled autonomy as those actions which in principle could be adopted by all the others. She identifies in particular rejecting coercion and deception as a fundamental ethical requirement based on this assertion. O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press. p. 97

[114] This proposal is a new interpretation of the idea of respect for persons from the Belmont Report. It seeks to increase respect for those patients who would not be considered fully autonomous by the healthcare provider by proposing "respect for persons" rather than autonomy as the goal to be achieved. Enzo, Aya, Taketoshi Okita, and Atsushi Asai. 2019. *What Deserves Our Respect? Reexamination of Respect for Autonomy in the Context of the Management of Chronic Conditions.* Medicine, Health Care and Philosophy 22 (1): 85–94., p. 85

be cultivated into various categories, such as decisional and executive autonomy.[115] Among these diverse reformulations, we maintain that the most promising proposal is the feminist reconceptualization of autonomy in terms of relational autonomy. According to Mackenzie and Stoljar,

> *"The term relational autonomy…does not refer to a single unified conception of autonomy but is rather an umbrella term, designating a range of related perspectives. These perspectives are premised on a shared conviction that persons are socially embedded and that agent's identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. Thus the focus of relational approaches is to analyze the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency."*[116]

The oxymoron of putting together "relational" and "autonomy" serves here to make us question the individual as a fully autonomous being. For instance, we insist on rights to autonomy for patients in clinical decision making, while in reality decisions must be "disposed of" by the doctor. In turn, we try to favor the individual's rights to independent choice, all the while ignoring the social circumstances in which these choices are made. Putting together the terms "relational" and "autonomy" suggests that these decisions are still those of the individual to make, but that they take place in a social environment in which others can help persons make these decisions. By using the relational autonomy perspective, we will examine the structural conditions for the development and shaping of a person's capacity for autonomy.[117]

Therefore, if we return to the idea of patient empowerment as a means to increase patient autonomy, what we mean is that possibilities to act (to be able to make choices, to be able to act autonomously) remain the most interesting part of this proposal. However,

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[115] Naik *et al*. argue that both decisional and executive autonomy are necessary for management of chronic disease. By decisional autonomy, they mean the ability to deliberate and make healthcare decisions, whereas executive autonomy means the capacity to execute the treatment plan. We object to the label of "executive autonomy" which suggests the patient will be able to undertake actions like an "executive" to manage his healthcare and also that he will "execute" the treatment plan. See: Naik, Aanand D., Carmel B. Dyer, Mark E. Kunik, and Laurence B. McCullough. 2009. *Patient Autonomy for the Management of Chronic Conditions: A Two-Component Re-Conceptualization*. The American Journal of Bioethics *: AJOB* 9 (2): 23–30.

[116] Mackenzie, C., and Stoljar, N., eds. 2000. *Introduction: Autonomy Reconfigured.* In: *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press. p. 4

[117] Dodds, Susan. *Choice and Control in Feminist Bioethics.* in Mackenzie, Catriona, and Natalie Stoljar, eds. 2000. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press. p. 214

we will have to add to this formulation, *with the help of others.* In other words, we seek an ethical disposition attentive to the vulnerability of the patient.[118] Rather than seeing full autonomy of the patient as the "desirable" trait to be achieved, relational autonomy allows us to see empowerment as an ongoing, dynamic activity, which will be hindered or enabled by the structural conditions (and persons) affecting that choice. It will also allow us to include the important role of others who "care about" the patient. The idea of "taking care" completes the concept of responsibility[119], in which it is no longer only a question of being responsible but also being called to a "responsibility for" those in need of assistance.[120] We will return to the discussion of responsibility when we introduce the capabilities approach in Chapter 3.

Preliminary Conclusion

To close this discussion for the moment, what comes out of these ideas of patient empowerment is what is missing. We speak of empowerment in terms of autonomy, in the idea of patients taking caring of themselves as if we could take care of a child or take charge at work. We imagine a self-sufficient individual ready to "manage" her disease. This idea of an autonomous and responsible person has been advocated for as part of a movement of a certain form of liberalization, insisting that the patient be responsible for her health, in a context where we are increasingly insisting on the limits of solidarity.[121] In an environment where the cost of healthcare is exploding, empowerment is being advocated for as an individual and collective responsibility. Patients are being told from an ethical standpoint that they have the "right" to become empowered because they are fully competent, capable citizens; while from an economic and political standpoint, we seek to impose this responsibility on patients due to the increasing economic burden of healthcare. There is thus hypocrisy in advocating for patients' rights from an ethical stance all the while encouraging it from a political and economic stance, especially by advocating for "rights" but using these "rights" as a means of imposing obligations. It could be that the needs of patients and the needs of healthcare institutions may correspond (after all, both

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[118] Pierron, JP. *Présentation. Prendre soin de la nature et des hommes*, 2014. *Classiques Garnier*, Paris. P. 9.

[119] For a discussion of Aristotle's ideas of responsibility used by Nussbaum in the capabilities approach, see Chapter 3.

[120] Pierron, JP. *Présentation. Prendre soin de la nature et des hommes*, 2014. *Classiques Garnier*, Paris. P. 11-12.

[121] Giroux, Elodie. *Les enjeux normatifs de la médecine personnalisée.* p. 70. In *Les valeurs du soin. Enjeux éthiques, économiques et politiques*, Paris, Seli Arslan, 2018.

are searching for the patient to be in "good health"), but they will not necessarily, nor always, do so.

Furthermore, if most of the tools of patient empowerment used today were developed to help healthcare providers work with patients, the wider role of society has not yet been adequately taken into account. We cannot only put pressure on the doctor or on the patient. We must also recognize our role (as citizens) to support patients to live as persons in society. In this thesis, we will therefore propose not only an ethical disposition for the individual patient but a wider political role for all of us as citizens. Putting all the pressure on the patient or on the doctor will not only remove us from the reality of patient empowerment, and it may further strain this important — but precarious — relationship. Patients live in society, and patients cannot live well with their disease if they cannot live well in society. We also cannot (yet) claim that empowerment has come from the "ground up" since we have not taken into consideration the patient's perspective in the formulation of patient empowerment programs.

Patient empowerment largely remains an ideal theory and has not been fully realized in any healthcare system today. As Robeyns points out, ideal theories are like mystical Paradise Islands, which tells us where the ideal lies, but rarely giving us the means to get there.[122] In this thesis, we are not seeking the healthcare providers and economists' *Paradise Island* by identifying the ways and means to achieve their ideal of patient empowerment. Instead, this thesis aims to give patients a voice: to let patients express what they understand and want from patient empowerment to enable the patient's view to emerge. We will however end this thesis with a concrete example of one healthcare institution that has been able to create a concrete life empowerment approach for a specific group of patients. This will not be a sort of *Paradise Island* that will show us the ideal without the path; instead, it will be an exploratory guide to inspire us toward the patient life empowerment approach.

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[122] Robeyns, I., Department of Philosophy, Florida State University, 2008. *Ideal Theory in Theory and Practice*: Social Theory and Practice 34, p. 345.

1.5. Biomedical Claims

We will now unravel the series of claims based upon the biomedical model in which patient empowerment stands to better understand its formulation in our healthcare institutions. When we refer to the biomedical model, we are referring to the dominant medical model in the Western World that looks at the physical or biological aspects of disease and illness, which are diagnosed, treated, or cured through the intervention of healthcare professionals. However our subject also crosses into social models of health, commonly conceptualized as the social, economic, and environmental determinants of health. Patients under the social model of health are often encouraged to become "empowered" through positive health behaviors.[123] However, we refer to these claims as "biomedical claims" as we will show how the biomedical model predominates in this discussion.

Steele *et al*. has proposed a list of biomedical claims for patient empowerment that we will use for this debate.[124] These biomedical claims are largely a given in patient empowerment discussions; they are often not explicitly stated, even if promoted. They are based upon the evidence-based medical (EBM) model.[125] One of the most commonly used definitions of EBM is, "*the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.*"[126] If EBM was initially in conflict with individual, variable clinical experience, it is being increasingly identified as complementary and as a way to improve clinical experience. One of the ways to do so is the use of clinical practice guidelines, which seek to provide a scientific

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[123] One reason for the link of empowerment and the social model of health was scepticism of modern medicine starting from the 1970s (which we discussed with LeFanu's analysis). McKeown's critique of modern medicine (which attributed the rise in the world's health to social and economic changes rather than to public health or medical intervention), appeared at the same time as the New Rights movements calling for individual responsibility in health in the United States, the United Kingdom, etc. Although the social model of health is supposed to focus on wider environmental factors influencing health, cost reduction also became part of this discussion. See: Colgrove, J., 2002. *The McKeown thesis: a historical controversy and its enduring influence.* Am J Public Health 92. P. 726-727.

[124] Steele, David J., Barry Blackwell, Mary C. Gutmann, and Thomas C. Jackson. 1987. *Beyond Advocacy: A Review of the Active Patient Concept.* Patient Education and Counseling 10 (1): 3–23. p. 7.

[125] Like patient empowerment, EBM has largely been expanded beyond its original use, such as the biomedical claims outlined here. EBM needs further conceptual precision to enable it to be a useful framework for clinical practice and research. I would like to thank Peter Wyer for this precision.

[126] Sackett, D.L., Rosenberg, W.M.C., Gray, J.A.M., Haynes, R.B., Richardson, W.S., 1996. *Evidence based medicine: what it is and what it isn't.* BMJ 312, p. 71.

foundation for clinical work, including in terms of efficiency, quality, safety, and consistency among healthcare practitioners.[127]

When EBM guidelines were initially introduced to provide tools to address clinical practice variation, they were rooted in the traditional perspective of the healthcare provider as the sole decision maker. New strategies, however, are taking into account the wider role of the patient and family member into these strategies.[128] One of the ways that patients and family members have been included has been in the rise of outcomes research to evaluate healthcare practices.[129] A key finding of outcomes research has been the link between patient adherence and healthcare outcomes in real world populations independent of other health-related behaviors.[130] Guidelines in this model therefore provide recommendations to promote adherence as an end goal of the doctor-patient relationship. It is in this context that the biomedical claims that we will discuss have been formulated.

The claims we will discuss can be summarized by the idea that both the patient and the doctor wish for patient participation and that this increased participation will enable better treatment outcomes. Taken alone, these biomedical claims are promising as they encourage the patient and the doctor to work together. The following is a list of the main assumptions, which are correlated with each other and sequential[131]:

1. *The patient wants to participate in healthcare decision making*
2. *The healthcare provider wants the patient to participate and helps them to participate*
3. *When the patient participates and the healthcare provider helps the patient to participate (1+2), this will allow a greater knowledge base for both parties. As a consequence, the healthcare professional will be able to develop a personalized treatment plan*
4. *Because of all of these factors (1+2+3), the patient will be more satisfied, and therefore they will be more likely to follow the treatment plan, leading to better healthcare outcomes*

What we are seeking from this investigation is to understand that even if this model is promoted, if it could be sufficient to allow patient participation, and if so, in what this

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[127] Timmermans, S., Mauck, A., 2005. *The Promises And Pitfalls Of Evidence-Based Medicine*. Health Affairs 24, p. 18.
[128] *Ibid.*, p.18.
[129] *Ibid.*, p.18.
[130] For one of the most cited articles on this subject, see: Rasmussen, J.N., Chong, A., Alter, D.A., 2007. *Relationship Between Adherence to Evidence-Based Pharmacotherapy and Long-term Mortality After Acute Myocardial Infarction.* JAMA 297, 177.
[131] This list is inspired from Steele's list but with some word changes for clarity/brevity.

participation consists. For instance, do the biomedical claims allow active participation for the patient, or does it impose it as a means of reducing healthcare costs?[132] Furthermore, in what temporalities can the patient participate, and what does this participation entail? Finally, what happens when this participation is not aligned with the biomedical claims, which link adherence and treatment outcomes? Let us start our discussion by questioning if the patient seeks an equal or even an active participation with their doctor, and if so in what temporality.

1.5.1. Patient Participation in Healthcare Decision-making

This research project will explore this first, starting question: what kind of participation are patients seeking in their healthcare? The patient's perspective will be developed from the second chapter of this thesis. However, for now, let us probe this question on a preliminary basis by showing the oxymoron in the terms we are using today. From the etymology of patient, we can derive the word *"patiens"* from Latin, meaning *"he that endures"* or *"he that suffers"* whereas actor (to use the French formulation of this term, *patient acteur*), is formed from the radical de ago, which means to *"push, act, led."* Being an actor of healthcare, or an empowered patient, presumes an agency coming from the patient. This means that it is partly the responsibility of the healthcare provider to open up the space for this activity and partly the responsibility for the patient to use it.

However, being sick means being (at least for a certain amount of time) vulnerable. Vulnerability implies that someone else may be responsible to "take care" of the vulnerable person (should it be the healthcare provider or the family) rather than the patient. This leads us to ask, how can a patient be both active and vulnerable? In other words, how can the patient be at the same time he that *endures* and he that *pushes* or *acts*? The doctor's and the family's participation are clear; they are acting on behalf of the patient. However, in patient empowerment, it is unclear what would be the action in which the patient should be engaged all the while being in a situation of vulnerability and

[132] Foucault's concept of biopower told us that the state seeks to control bodies in order to make them "fit for work." This suggests that even if the origins of patient empowerment may stem from diverse movements such as the civil rights movements, the reason that they are being championed and promoted today at least partly stem from economic logic seeking cost reduction. In other words, if we agree with Foucault, this means that we are seeking to make patients empowered in order to reduce healthcare costs (such as hospital admission, unnecessary treatment plans, and costly medical interventions). Thus from an economic point-of-view, patient empowerment will be desirable if it is linked to cost reduction as well as enabling the patient to re-enter the workforce.

dependence on healthcare services. In a minimalist formulation, this suggests the patient may only be the actor when she is no longer the patient: that is when she leaves the doctor's office and returns to society, when she becomes the "manager" of her treatment. However, admitting to that formulation means giving a more passive participation to the patient in the healthcare relationship, which is exactly what many formulations of patient empowerment are trying to overcome. Therefore, there seems no easy answer to how the patient can be "one who endures" or "one who is dependent" on the healthcare system and concurrently "one who acts" (and whether this activity is even desired by the patient).

In addition, a nuance is often forgotten in Parsons' oft-quoted phrase of the "sick role": he saw illness as a type of "deviant behavior" due to a withdrawal into a dependent relation. Parsons said that the situation of the sick person, *"places him in special relation to those who are not sick, to the members of his family and various people in health services, especially physicians…*"[133] As the sick role implies being taken care of by others, according to Parsons, it also provides leverage for social control of those dependent persons. Thus according to Parsons, the sick person "will not burn his bridges" as he is dependent on that system.[134] Thus it will be important to ask if the power relations between the doctor and the patient have actually been redistributed in this "new model" of patient empowerment, and if so, to what extent and under what circumstances. If we return to the etymology of the word *em-power*, we can see an implication of healthcare providers giving patients the power to manage their healthcare; this means again that this authority is for healthcare providers to give.

Furthermore, we need to ask if in leaving the sick role, the patient's behavior is now longer deviant, and what that implies for both the doctor and for the patient. If the person is no longer in the sick role, for instance, does that mean she can no longer claim exception from responsibility?[135] In practice (at least so far), we do not "impose" participation on the patient. However if we expect from a cost/social point of view that

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[133] The model developed by Parsons was originally developed for acute (rather than chronic) disease; thus it must be taken with precaution. However we can still see some recurring elements of Parsons' categorization of the sick role for chronic disease, in particular the idea that being sick is undesirable and may interfere with returning to workforce; thus patients are urged to be "taken care of" and to seek technically competent help. See: Parsons, Talcott. 1968. *The Social System*. Free Press, p. 312

[134] *Ibid.,*, p. 285

[135] Parsons identified the following responsibilities from which the sick are exempt: 1. Social role responsibilities, relative to the severity of the illness. Parsons said that this concept has a moral connotation and often is "forced" upon the patient to prevent his "malingering." 2. The patient is not responsible to "cure" himself; thus he needs to be "taken care of." 3. Being sick should be undesirable and therefore there is the obligation to want to get well. 4. There is the obligation to seek technically competent help, as the patient does not know what needs to be done or how to do it. *Ibid.,* p. 436

patients must be empowered to reduce costs, then we could be on a path which expects or even imposes patients to take on this responsibility, thereby saying that patients can longer claim exception from the sick role. This is a risky proposition as it is neither always desirable nor feasible, either for the patient or for the doctor, at least not in all temporalities of the patient-doctor encounter, and it will never be so for all patients. Let us further explore some of these difficulties now.

Temporality of Patient Participation

In what temporality is the patient expected to be active in healthcare? Do we mean this to take place at the diagnostic stage? When the patient is trying out medication? When the chronic disease is at least somewhat stabilized with medication and the person is expected to "get on" with their lives? If most formulations of patient empowerment take place at the stage of disease management (when patients must take long-term medication regularly), a reformulation of the patient-doctor relationship based upon the biomedical claims highlighted above would suggest that the patient should be able to participate from the diagnostic stage in order to allow the doctor to better diagnose and treat the patient. However, patient empowerment from the diagnostic stage poses a number of difficulties that we will now investigate.

In the first place, let us discuss the meaning of chronicity. The word chronic derives from the Greek word *chronos* and simply refers to the passage of time.[136] If we can roughly define a chronic disease as one that either persists for a long period of time or reoccurs, then a disease becomes chronic when it is constant or persistent over time. However, a disease is only recognized as chronic when it is diagnosed (or in other words, filtered through medical expertise); therefore, in the diagnostic phase, it is not necessarily chronic, as the diagnosis has not (yet) been discovered. Furthermore, it is also not necessarily chronic in the treatment phase, if a cure can be found for the disease. Therefore, a disease is only chronic when 1) it has been recognized as chronic by a medical professional; and 2) due to the disease itself, or its inability to respond to treatment, it becomes chronic. Disease therefore exists in a temporality before, during, and after the designation of it as a chronic disease via medical expertise.

[136] von Peter, S., 2010. *The Temporality of "Chronic" Mental Illness.* Cult Med Psychiatry 34, p. 13.

Foucault argued that time has become a category to impose biopower.[137] The idea of chronic disease appeared for the first time in the post-World War II period,[138] with the collective organization of healthcare in clinical medicine which sought to keep patient records, implement an appointment system, as well to regulate populations through public health measures.[139] Our current ideas of chronic disease have been linked to these social practices, in particular the clinical consultation, which at least partly regulates the temporality of the chronic disease within the collective organization of healthcare. In the discussion that follows, we will question if patient empowerment can be understood through such temporalities as the clinical consultation's diagnosis, treatment experimentation, and management phases. Our principal interest in this discussion is whether or not the temporality expected of patient empowerment is realistic for the patient. However, we should also not presume that the patient's experiences of time align with the collective organization of time.[140]

1. Diagnostic Phase

To further unravel this difficulty, we will take one of Michael Balint's[141] classical clinical tales for inspiration (Case No. 1)[142] to start our debate on the patient's participation[143] from the diagnostic stage:

> *A young woman, married, without children started complaining of epigastric and thoracic pain at the start of the year. She was sent to a specialist who found her thorax completely normal. The patient, however, continued to complain about pain, so she was sent to a radiologist. This physician also said there was nothing wrong; however, he suggested that they could try a massage for her pain. The massage did not work. She still had pain. There followed a series of unnecessary medical procedures, lasting several years, including the removal of her appendix. Still, the pain persisted. Finally one day the primary care doctor gave her a long interview and the patient discussed the stress of having children with a husband often absent,*

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[137] In the *History of Sexuality*, Foucault was referring to control of bedtime, etc. Foucault, M., 1997. *La volonté de savoir, Histoire de la sexualité*. Gallimard, Paris. p. 39.
[138] The term "chronic" appeared for the first time in the *Index Medicis* in 1950. Armstrong, D., 2005. *Chronic illness: epidemiological or social explosion?* Chronic Illness 1, p. 26.
[139] Armstrong, D., 2005. *Chronic illness: epidemiological or social explosion?* Chronic Illness 1, p. 27.
[140] Von Peter for instance proposes different categories for the patient's time such as "creative time" and "relational time" which do not fit into the model of time organized around the clinical consultation. See: von Peter, S., 2010. *The Temporality of "Chronic" Mental Illness.* Cult Med Psychiatry 34, p. 13.
[141] Balint, Michael, and J. P Valabrega. 1988. *Le médecin, son malade et la maladie*. Paris: Payot., p. 19
[142] This case history is summarized rather than quoted for brevity. *Ibid.*, p. 19-21
[143] An active role for the patient was not the priority of Balint's classic work. It was more focused on a critique of the illness model of medicine and also the lack of a fruitful relationship with the patient because of this model.

> *and a brother who had been dying at the time her symptoms started. Remarkably, after this interview, her symptoms improved. Between the time of the first and the last interview, however, four years had passed.*

Balint used this example to critique modern medicine's desire to seek diagnosis before treatment. The case study described here sought to bring insight from psychiatry on how to work with patient narratives to uncover the causes of illness or disease. His emphasis in working with general practioners was to improve their listening skills in order to better diagnosis the disease. In the case study described above, he emphasizes the unnecessary costs and painful medical procedures that could have been avoided if the doctor had simply taken the time to listen to the patient.

However, the case study is interesting for another reason from our enquiry into the temporality of patient empowerment. We can say that the doctor's role is to work actively to find the diagnosis. In return, the patient will participate by telling useful information to the healthcare provider to enable the doctor to find the diagnosis. However, what information exactly must the patient "tell"? And which information is "useful"? In other words, is it now the responsibility of the patient to tell their whole biography to enable the doctor to better diagnosis the illness, or is it still the task of the doctor to "dig out" relevant details? In other words, where are we now placing the responsibility: in the hands of the patient or the doctor?

Is it difficult to understand patient empowerment from this stage of the doctor-patient relationship. Was the patient "empowered" because she followed the doctor's advice to see various specialists? Or can we now say that, being no longer exempt from the sick role, that she was hiding information from the doctor, leading to unnecessary medical interventions (and costs for the healthcare system)? Thus was she an empowered patient because she sought — and followed — the advice of the doctor to help him find a diagnosis (by any means necessary, including the removal of her appendix?). Alternatively, was she unempowered because she did not help the doctor to find the right diagnosis by providing all possible details, both intimate and embarrassing? This raises the question if, in patient empowerment, we are asking patients to "reveal" themselves to help the doctor diagnosis and treat disease, blurring the domain of the medical, but also of the psychologist, of the family, but especially of the patient's personal domain. Balint makes the argument that these details helped the doctor find the source of the problem. Therefore

the inclusion of this information was helpful for the doctor[144]; however, he does not elaborate on whether sharing these details was helpful to the patient herself in the sense of how she understood and lived this event. Furthermore, which details are relevant for the doctor? We cannot really expect patients to know what information will be useful to the doctor at the diagnostic stage.

However, perhaps we can put the responsibility on the doctor by saying that that he was not adequately doing his job by taking the time to understand the patient in his globality? This is a common charge against healthcare providers today: *if only the doctor had taken the time to understand me, I would have a quicker diagnosis and a better treatment plan.* This could certainly be Balint's perspective if we formulate it with our modern economic concerns; however, it will need to be supplemented with the necessary means (especially time in the clinical encounter) which our current healthcare infrastructure is taking away, rather than expanding. Therefore, more information of this type could help the doctor, but it could also add unnecessary work, as many details will not be relevant for the diagnosis and the treatment plan. In addition, it places all the responsibility on the doctor, which is neither reasonable nor feasible when we understand the limits of the doctor's intervention, of modern medicine, and of the patient's desire to reveal this information. It is also not satisfactory in terms of patient empowerment, which seeks more participation for the patient, not giving more responsibility to the doctor.

If we expect that patients will provide all details, banal but also embarrassing in the clinical encounter, we are imposing obligations, not protecting rights to participation. We are taking away the agency that the ideal of patient empowerment is seeking, even if leading to a better diagnosis as the doctor knows the patient's full biography. At the diagnostic stage, imposing (or even encouraging) patient empowerment would impose an action (telling all relevant details), of someone who is incapable of judging this information as useful. It also raises privacy concerns for the individual. We therefore maintain that conceiving of patient empowerment at the diagnostic stage could lead to a slippery slope where the patient could be accused of "wasting the doctor's time and resources" by not revealing all, necessary information, as well as a difficult situation for healthcare providers to prove that they acquired all the necessary information from the patient.

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[144] "*If the doctor does not try to get this information, his decision will be blind.*" (our translation): Balint, Michael, and J. P Valabrega. 1988. *Le médecin, son malade et la maladie*. Paris: Payot, p. 68

2. Post-diagnostic Phase

Having clarified the difficulties for the patient at the diagnosis stage, let us now move to the stage post-diagnosis, that tricky stage for the patient in which the patient is both relieved to have a diagnosis yet anxious about living with it. This post-diagnosis stage we wish to highlight is a space *in between*: when the diagnosis has been announced but the regular treatment has not yet been discovered and/or implemented. It is in essence a further diagnostic stage, although this time it is for the diagnosis of an effective treatment rather than the diagnosis of the disease. It could also be called a time of "wait and see," "let nature do its work," or a period of "active experimentation" by the healthcare provider to find an effective treatment plan. The doctor in this stage remains a full actor, investigating, trying out, experimenting, researching new treatments. However, it is questionable whether the patient has left Parson's sick role. The patient at this stage is still "waiting" "depending" "hoping" for the assistance of medical solutions and the doctor to propose them. The patient is immersed in uncertainty about what the disease and the treatment will mean for her in her life. At this stage, the patient may undergo a mourning for her health or liberty, as well as the certitude that accompanied life before the disease.[145] It is the stage that the disease can be lived as a catastrophe, a shaking up of the sense of one's existence and identity for both the person affected and for others who can no longer find the person they know.[146]

In addition, there is another troubling factor for the patient in this temporality. If in some conditions, this period could merely be the time the diagnosis is clarified and the prescription is in hand, in other, more complex conditions, this period can last several months, several years, or even several decades. In the case of refractory epilepsy, for instance, finding the right combination of drugs to stop seizures is often a trial and error process that can last years. Epilepsy is also a dynamic disease, changing in time. Thus the drug regimen that worked for a certain period can suddenly stop working and the process to find an effective treatment can start all over again. Doctors, with their scientific knowledge of drugs and drugs combinations, are the main actors in this stage of trial and error, as they research, prescribe, and test treatments, mobilizing their scientific expertise to the largest extent possible to find an effective treatment plan for the patient.

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[145] Barrier, P., 2014. *Le patient autonome*. Puf, Paris. p. 24.
[146] Marin, C., 2016. *La maladie, catastrophe intime*. Presses universitaires de France, Paris. p. 6.

The patient's participation, however, is ambiguous. If patients are encouraged to be active in the sense of adherence, to show to the doctor whether the drug regimen is working, and to verify that there are no significant side effects, they mainly participate by providing the body to experiment the drug combinations and to report back on these experimentations. It is difficult at this stage to see how the patient can reasonably dialogue with the doctor in an equal footing about which medications and combinations of medications they should try as the decision is based upon the doctor's intuition and expertise. We will discuss in a later section what experiential knowledge or expertise the patient may mobilize; however, for the moment, let us understand this through the patient's perspective. As a patient with epilepsy in this research project stated, *"I have diverse types of seizures! It seems that it's exciting for the neurologists. It's for that reason I have the impression of being a guinea pig. I am a mystery for certain doctors, you see, because they don't really know what to give me as a treatment so that it works! So they say to me, 'well, we're going to try that!' Yes, we will cross our fingers, 'hey, let's go!'"* Even though this patient uses "we" in the citation of her doctor, "we're going to try that!" (perhaps showing how the doctor interprets this exchange), she herself experiences this situation as an object, with the doctor performing experiments on the animal subject (the guinea pig). The patient experiences this stage in a passive way while the doctor is in the period of active investigation ("we're going to try that!). For the doctor, it can be an exciting period, in which he can advance both individual patient treatments as well scientific understanding of the disease. However, for this patient, this stage is more extreme the "sick role": it could be even called the "lab rat" role.

Let us ask this patient in what way she can participate in this stage with the doctor, even if she feels at times like a lab rat. She says for her, at this "experimental stage" (which has unfortunately lasted several decades), being active means, "*They (the doctors) make me propositions; they tell me, 'you can do that and that and that.' And following the propositions that they give me, for some I say, 'no, let's eliminate that' or I let them decide. When there is something I don't understand and it's important, I ask."* From this dialogue, we can see that the patient has identified several rights in line with French legislation, namely the right to agree with or to negate the doctor's proposition and the right to information. However, an active participation is for the doctor, who "proposes" the medication and in return "negotiates" and "tries to convince" the patient to try and take the treatment he is proposing. Thus the patient's capacity to participate is largely negative: she can show her rights by refusal. She can also propose certain modifications of the treatment,

such as the treatment schedule based on her own experiential knowledge of her disease; however, there is no partnership in the sense of co-decision. The doctor acts and the patient is acted upon. The only thing that has changed is that her accord has been actively solicited (because of the requirement of informed consent) and is encouraged (from the doctor's desire and obligation to have her informed).

Thus at both the diagnostic stage and at the level of treatment experimentation, the participation of the patient is precarious and unclear. If we put responsibility on the patient to help the doctor in his diagnosis, we could be on a slippery slope infringing on the personal domain; however, as we have seen in the treatment experimentation phase, we could be putting both unrealistic demands on the patient and the doctor for greater inclusion of the patient. Even if this situation is unacceptable for the patient (who describes herself as a guinea pig), it still seems difficult to conceive of active participation for her in the treatment experimentation phase other than refusing certain treatments or proposing different treatment timings.

3. Long-term Treatment Phase

Therefore, the stage that seems to hold the most potential for patient empowerment is the long-term treatment phase, in which the medication has been found and the patient is expected to regularly take her medication and to engage in other healthy behaviors to manage her disease. We will investigate these claims at a later stage. However, before leaving this section, we should highlight that the "treatment in daily life stage" often crosses the "treatment experimentation phase" for many patients, especially those that search on a long-term basis for the right treatment, as is the case for refractory epilepsy.

Therefore, the question remains of when exactly the patient empowerment process should begin. We could argue from an ethical stance that the treatment experimentation phase is the starting point because patients risk being on those medications for the rest of their lives, and that whether short or long term, the medication affects *their* bodies. Therefore, from this stage it would seem to be vital to ensure the patient's inclusion both so that the patient adheres to the treatment plan (from the biomedical perspective) and so that she agrees with the treatment plan (from the ethical perspective). However, for that to happen, the patient must be ready, willing, and capable of leaving the sick role. The doctor must also see the patient as capable of leaving the sick role and see it as valuable.

1.5.2. Patient Participation for the Doctor

Now let us turn to the doctor's perspective of empowerment. Under Claim 2, there are two presumptions that we will discuss: the idea that the healthcare provider *wants* the patient to participate and the idea that the healthcare provider *helps* the patient to participate. Therefore, there is a question of both *desires* (wanting the patient to participate) as well as *acting* on those desires (helping the patient to participate). We will turn our focus on the doctor-patient relationship, although, of course, the necessary participation of other medical personnel (especially nurses in models such as therapeutic patient education) is not to be forgotten.

First, does the healthcare provider want the patient to participate? This idea is problematic both as a generalization and as a realization. In the first place, it must be answered on an individual basis if an individual doctor (openly or secretly) actually want patients to participate in an active way.[147] There is, of course, the presumption of power relations in this statement, as it implies asking whether the doctor wants to give some decision-making power to the patient. We will not presume to answer for each individual healthcare provider and research on this subject is scarce; however, a 2017 online Medscape poll of healthcare providers has shown that three quarters of healthcare professions interviewed[148] feel that an active patient was helpful in the medical encounter. In addition, 43% felt that patients who research their symptoms and/or treatment options typically have better outcomes than patients who do not. This largely coincides with my own research that showed that healthcare providers see a correlation between an empowered patient and treatment outcomes. Therefore, let us assume from these two sources that at least a certain number of healthcare providers see the potential of patient empowerment in their practice.

As at least some doctors see a correlation between empowered patients and treatment outcomes, it will be interesting to investigate if patients can help them (as doctors) to better fulfill their professional missions. In other words, if an active patient is helpful in the medical encounter, is it only helpful for the patient? We will use Parson's

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[147] For a French study on how religious belief might influence how patients (and doctors) may see patient participation, see: Fainzang, S., 2001. *Médicaments et société: le patient, le médecin et l'ordonnance*, 1re éd. ed, Collection "Ethnologies-controverses." Presses Universitaires de France, Paris. For specific examples of doctor's visions of patient participation in terms of religious beliefs, see p. 126.

[148] This was a small poll of around 1089 healthcare professionals, which included doctors, nurses, and other healthcare professionals: Do You Value "Empowered" Patients? [WWW Document], n.d. . Medscape. URL http://www.medscape.com/viewarticle/882548 (accessed 2.18.19).

definition of the doctor's mission as the ability to use his technical skills to "do everything possible" to facilitate the diagnosis, treatment, or recovery of the patient.[149] Therefore can an empowered patient help doctors fulfill their responsibilities to facilitate the patient's diagnosis/recovery/illness management? This is not an easy question to answer, because while the patient's participation is said to have changed, the doctor's responsibility is still largely the same. What has changed from the healthcare providers' perspective, of course, is the *modus operandi*, the way of interacting with the patient, which could potentially change their way of going about their work.

Balint's idea of the mutual investment company[150] and Engel's biopsychological model[151] proposed that a doctor-patient partnership both benefits the patient and the doctor by enabling both a better diagnosis and treatment plan. In both theories, there is a responsibility on both sides: Balint's required a deep and long-lasting relationship between family and doctor[152] through what he called the "mutual investment company"; while Engel sought a methodology to make the patient interview scientific through a three-step process: observation (outer-viewing), interspection (inter-viewing), and dialogue (interviewing). Engel says that, "*the patient and doctor need to be allies…certain writers say now that patients should learn how to take care of themselves…that misses the point. That still assumes that the doctor is the authority who knows everything. The emphasis has to be on what doctors learn from what patients have told them.*"[153]

Under these formulations, the empowered patient is a partner with the missing information to help the doctor to do a better job. Both think that they will help the patient (with a better treatment plan) and the doctor (with a more complete assessment of the person with the disease), and both of them (with a more fulfilling relationship of mutual assistance). However, these approaches have been increasingly questioned for failing to achieve their main purpose: an integrative approach between the disease-centered model of

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[149] Parsons, Talcott. 1968. *The Social System*. Free Press., p. 447

[150] Balint, Michael, and J. P Valabrega. 1988. *Le médecin, son malade et la maladie*. Paris: Payot., p. 144

[151] Engel, George L. 1997. *"From Biomedical to Biopsychosocial: Being Scientific in the Human Domain."* Psychosomatics 38 (6): 521–28.

[152] Balint thought of this relationship as specific to family medicine; however, in the case of serious chronic disease (such as epilepsy), it could be extended to specialists as some see patients for years and sometimes generations and sometimes have a relationship with their families. This was the case at one of our research sites, the Teppe.

[153] Morse, Diane S. 1996. *"A Family-Oriented Interview with George L. Engel, M.D."* Families, Systems, & Health 14 (4): 413–24., p. 423.

illness and the subjective factors of the person-centered approach.[154] In day-to-day clinical practice, they have largely failed to change the practice of the doctor who seeks to provide better care (from a humane stance) while also providing technical knowledge (from a biomedical stance).[155] However, we would like to add that they have also not resolved the problem of the potential cost to the patient. As we have already suggested in the previous section, providing every possible detail to the doctor is neither the patient's prerogative nor obligation (or at least, our modern healthcare systems have not yet punished the patient for hiding or lying about personal details that could be relevant). Therefore, in the case of patient empowerment, if these models suggest a way forward to enable the doctor to have a more global view of the patient, the question remains if the doctor will also benefit from this knowledge, both in terms of a better relationship with the patient but also in development of a better treatment plan.

Let us further explore this idea by looking at the different definitions and conceptions of patient empowerment given by healthcare providers and patients. In the Medscape poll, the majority of healthcare providers interviewed said that patients conceived of empowerment in a different way than doctors (61%), while also stating that they thought only about 25% of their patients were empowered.[156] While the poll did not discuss what counts as empowerment to patients, the poll asked healthcare providers to tick their vision(s) of patient empowerment in the following categories: (1) patients making decisions about treatments; (1) patients asking questions about the disease and/or the treatment; (2) patients proposing possible treatments to the healthcare provider; (3) the patient showing up for the visit and follow-up visits; (4) the patient accessing health records; (5) the patient requesting the track record of the physician and/or the success rate for a given treatment.[157]

In the first place, all of these definitions take place within the temporality of the patient-doctor encounter. They do not propose patient empowerment as activities beyond the clinical encounter. This suggests that those who devised the pool saw patient

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[154] Benning, Tony. 2015. *Limitations of the Biopsychosocial Model in Psychiatry.* Advances in Medical Education and Practice, May, 347.

[155] Weber argues that this model has led to a new objectification through questionnaires and other forms of evaluation. In addition, they have created even more divisions between the patient and healthcare providers (i.e. the doctor takes care of the biological aspects, while the psychologist or social worker takes care of the psycho/social aspects). See: Weber, J.-C., 2017. *La consultation*, Presses Universitaires de France. ed. Paris. p. 57.

[156] Do You Value "Empowered" Patients? [WWW Document], n.d. Medscape. URL http://www.medscape.com/viewarticle/882548 (accessed 2.18.19).

[157] *Ibid.*

empowerment within the confines of the doctor-patient relationship or that the only means of measuring empowerment for doctors was within this encounter. In addition, none of the answers defined as patient empowerment by the poll follow Balint's and Engel's ideas of the patient giving the doctor useful information. Instead the questions provided are a mixture of *patient rights* (the right to health records, patient information), *disease management* (showing up for doctor's visits), and *evaluation of the doctor's expertise* (the track record of the physician). These categories are focused more on helping the patient make an informed decision about their disease and their healthcare provider (thus helping the patient), rather than on helping the doctor. If we can presume that a more informed patient could in turn help the doctor with his treatment plan, the line is neither straightforward nor suggested in the poll. In addition, some of these categories do not require much investment from the healthcare provider, such as having the patient show up for visits and follow-up visits, or requests by patients to access their health records. However, others might involve a considerable time investment (patients proposing their own treatments, discussion of various treatments and answering questions about these treatments); while others might make it difficult for the healthcare provider to answer, as they could put the doctor's professional expertise into question (i.e. the track record of the physician or of the treatment).

While these categories of patient empowerment reflect a certain person-centered approach (such as providing information for the patient to make an informed choice), they do not necessarily take into account the responsibility of the doctor (their values and definitions of patient empowerment). This is a problem, as the vision of patient empowerment for the healthcare provider will likely influence the means in which the healthcare provider will help the patient participate (Biomedical Claim 2). This claim assumes that the patient will envisage their participation in the same way as the healthcare provider (despite the doctor's recognition via the poll that the patient's and the doctor's conceptions are different). In addition, the claim we have been discussing assumes that healthcare providers' visions are the same. Therefore, it does not help us to understand how to give greater agency to the patient's vision of participation in the encounter, as it still the doctor's place to make space for the patient.

Therefore, we have not solved the question of whether the doctor sees a benefit of patient participation, with the mission to "do everything possible" with technical means and knowledge for the patient, nor how doctors will do so, if they have different visions of patient empowerment. This suggests at least some doctors see patient empowerment as a

benefit to the patient rather than (necessarily) to the physician. This raises the question of why the doctor would then favor an active patient in the encounter. Of course if we presume that if patients are empowered, then they will be more adherent to their treatment plan (Claim 4 in the Biomedical Model), then it is likely that the doctor will wish a more active role for the patient. We will be further discussing this question under the concept of expertise (Claim 3). If doctors consider that patients also have a right to participate from an ethical point of view, then they will likely also try their best to encourage patient empowerment in the encounter. However, if these links are not straightforward, patient empowerment could fall into the trap of "when we have time." Patient empowerment thus becomes a privilege rather than a prerogative.

If we can understand that doctors will not (necessarily) see an empowered patient as important for their practice, this means that we will need to have a larger vision of patient empowerment than just the patient-doctor relationship and include the healthcare infrastructure in place. This is necessary as patient empowerment would appear to enlarge the healthcare provider's mission as well as the responsibility (to help the patient), without considerable benefit to the healthcare provider. Even if doctors support the idea from an ethical point of view, or by thinking it will help treatment outcomes, they must have the means to make it happen. This goes beyond the legal cadre and includes the feasibility within the institutions themselves due to increasing time and resource restraints. According to the Medscape poll, 44% of healthcare personnel said that patients who bring their own research on their condition require more than the allotted time to discuss their findings. Thus there is a potential disconnect between what is potentially the patient's and the doctor's desires for patient participation and the reality of the healthcare system in place.

It is often argued in patient empowerment discussions that empowered patients take more time on a short-term basis as they require discussion, negotiation, and agreement between the patient and the healthcare provider. However it is thought that in the long-term there will be less time needed as the patient will be more adherent and take care of his own health (Claim 4). However, this statement shows that patient empowerment may take more time, at least in the "short term." We should therefore ask healthcare professionals if patient empowerment adds an additional time burden to their otherwise stressful practice, de facto preventing doctors from being "better doctors" from their perspective (increasing burn-out, etc.). If doctors do not see the active patient as useful or feasible, then the discussion could end there, although it would likely be questioned from an ethical point of view. If doctors do see it as useful, however, but unfeasible, this suggests that we would

need to give more time in their practice to facilitate it. This helps us see that the question of patient empowerment is not (only) about doctors' subjective feelings on the matter, but also with the institutions that regulate and support them. Hermann Simon (1867-1947)[158] coined the idea later taken up by Jean Oury[159] of "healing the institution": in other words, it is not only a question of healing the sick or supporting the individual healthcare provider; it is also a question of healing the institutions that support them.[160] Thus, patient empowerment is wider than the doctor-patient relationship, and putting responsibility solely on the doctor or on the patient will be likely fail if the healthcare system is not ready to support both of them in this process.

1.5.3. The Personalized Treatment Plan

We will now move to biomedical claim 3, the formulation of the personalized treatment plan. When we use the word personalized in this section, we are talking about the idea, present since Hippocrates' conception of care, to mean finding the right treatment for the individual at the right time. The word personalized suggests that the treatment plan will be adapted to the particularities of each individual person, or the hope that somehow the treatment plan will be adapted to take into account each person in their singularity. As patients, we are not only waiting to be correctly targeted by the treatment, but to take into consideration ourselves, this ourselves indicating an individual non reducible to our disease.[161] However, personalization of healthcare comes with certain limits such as the ability to deal with patients' expectations in the collective organization of healthcare.[162]

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[158] Simon, H., 1929. *Une thérapeutique plus active à l'hôpital psychiatrique*, Ed. Walter de Gruyter (trad. fr. Hôpital psychiatrique de Saint-Alban), Ed. Walter de Gruyter (trad. fr. Hôpital psychiatrique de Saint-Alban). ed. Berlin and Leipzig.

[159] Oury envisaged a collective responsibility for all actors in order to provide the best care for the patient. He believed that only by giving liberty, initiative, and responsibility to all actors (healthcare providers or patients) that we can heal our institutions. An example of this kind of collective responsibility can be seen in the final section of this thesis, when we discuss the collective responsibility of patients and personnel at the Teppe. For more information on Jean Oury's ideas, as well as a history of the main ideas inspiring evolving approaches to psychiatric care, see: Oury, J., 2007. *Psychanalyse, psychiatrie et psychothérapie institutionnelles.* VST - Vie sociale et traitements 95, 110–125.

[160] de Luca-Bernier, C., 2011. *Logique du soin en psychothérapie institutionnelle*. Le Coq-héron 206, 98. Referring to : Simon, H. 1929. *Une thérapeutique plus active à l'hôpital psychiatrique*, Berlin et Leipzig, Ed. Walter de Gruyter (trad. fr. Hôpital psychiatrique de Saint-Alban).

[161] Weber, J.C. *l'individualisation des soins: des modalités multiples.* In : *Les valeurs du soin: enjeux éthiques, économiques et politiques*. Editions Seli Arslan SA. 2018. p. 44.

[162] *Ibid.*, p. 46-47.

However, the idea that the (activated) patient and the (activated) doctor will be able to participate toward a personalized, patient-centered treatment plan by bringing specific knowledge (or expertise) to the encounter remains the most attractive formulation in the biomedical model of patient empowerment. It gives us a vision of a partnership, in which both the patient and the doctor work together to develop a singular plan that will be both acceptable to the patient (from their perspective) and to the doctor (from their professional perspective). It would also seem to "repair" a relationship said to be increasingly precarious, complex, and fragile.

In this section, we will look at the problems brought by both the patient and the doctor to this individual relationship. In order to investigate this claim, we will need to know what knowledge is brought to the encounter by the patient that is useful for the doctor, in order to solve the problems we have highlighted in Claim 2. In order to make sense of the idea of a certain knowledge — or expertise — that each party can bring to the relationship, let us now return to the discussion of whether power relations between the patient and the doctor have somehow been destabilized. While a tantalizing idea that this age-old asymmetrical healthcare relationship could be turned on its head, we have to first question if this relationship has *actually* been destabilized.

To make an (obvious) point, it is not to be expected in the age of "patient rights" that doctors will disappear or even that their epistemic authority will be nullified in the age of chronic disease; on the contrary, we are living longer. The longer we live the more likely we have several complex, chronic conditions, which require long-term and careful medical supervision by the healthcare provider due to a multitude of pharmaceutical and technical solutions. In this age of chronic disease, but also technical complexity, we need the expertise of healthcare providers more than ever to be able to navigate the complex organization of our diseases. Doctors provide us a service — and this service is deemed essential by many of us — but also by our institutions which regulate this service. Even in China, where family medicine remains a hallmark of prevention, Chinese patients seek out doctors (Western and TCM) when they see their disease as "chronic" or "serious" and believe that they cannot manage their disease[163] on their own or with their family's help. As patients, we continue to seek what we call "expert" advice to treat our diseases, because generally we accept the idea that doctors — with many years of medical training — still know more than "us," the "laypersons," who have not received that training. We also

[163] Based upon interviews conducted within this research project

accept that we have an obligation to pay them for the healthcare act (whether directly or indirectly depending on the healthcare system) because of this professional, expert service they provide. If it is now acceptable to go to others for (further) advice, such as patient associations, Internet forums, informal discussions with other patients, these alternative forums have complemented, not replaced the medical encounter, both in terms of expertise and institutional authority to treat the disease.

Thus, the idea that the epistemic authority of the doctor has been turned on its head in the age of patient rights is largely a misnomer. It is also potentially dangerous, as it hides the reality that the patient remains dependent on the healthcare provider (as Parsons told us), and if anything, the doctor's epistemic authority is as strong as ever (as described by Le Fanu). Therefore, it is more accurate to say that patients have gained awareness in recent years about the realities of medical care and that they have been given certain rights in law, which (in theory at least) may allow them to participate more fully in the healthcare relationship. However, it is not accurate to say that this asymmetrical relationship has somehow been "turned on its head" as it is still the doctor that "prescribes" and the patient that "disposes" of this prescription. Even though we are aware that doctors are not "gods" that can magically cure us, we still rely on their expertise and guidance to help us live longer, more active lives. This expertise is the best possible choice, under the circumstances, for most of us. However, this expertise reveals a certain tension in our societies as a whole: we need this expertise given increasing technicity and specialization, yet somehow we resent it for its hold over us because we seek greater freedom of choice. We are fairly privileged, however, as we have the possibility to seek out alternatives, but we are still safe in the knowledge that we can always return if these alternatives are ineffective.

Healthcare Provider Expertise

It is often promoted in patient empowerment discussions that the patient also has an expertise to bring to the medical encounter. We will need to more fully understand this idea to unravel the slippery idea of patient empowerment. However, let us first explore the idea of the healthcare provider's expertise to elaborate on both the place and legitimacy of the doctor's expertise in the doctor-patient relationship, before moving on to the patient's expertise.

In the first place, we should ask under what conditions a person can be considered an expert. At least two conditions pertain to expertise: the first is the person's knowledge

and the other the skill or performance ability.[164] For the healthcare professional, expertise is gained from academic studies (the person's knowledge) but must also be applied with skill in real life clinical situations (the skill or performance ability). Thus, the healthcare professional must both have the knowledge and be able to apply skills with this knowledge in real life (i.e. diverse and variable) situations. As doctors must apply this expertise to care for individual patients, unique in both their diseases and in their biography, their expertise is particularly challenging to acquire, maintain, and especially to master. As Jean-Christophe Weber expresses it, this *technê* requires skill combined with a crafted inventiveness to adapt to each situation and person. Medical expertise can thus be constantly improved.[165]

Relational Expertise

However, it is not enough to gain knowledge and to use it to be considered an expert. Scholars also recognize a relational component to expertise. This recognition can be divided into two aspects: (1) recognition by other experts and (2) recognition by those whose expertise it is designed to help (non-experts). To investigate the first idea (recognition by other experts), what we mean by this is that you are not an expert unless someone (usually an expert) recognizes you as one. That someone is generally capable of assessing that expertise, which means a fellow expert. Here the legal cadre comes into play under legislation[166]: the doctor remains the expert authority allowed to dispense of the healthcare act, to prescribe medication, and the patient physically comes to the doctor's place of business in order to receive the healthcare service because the doctor has been given the epistemic authority (they are evaluated and regulated) under law. As citizens are in essence also representations of our institutions, we (at least in theory) agree with this organization, or more accurately we participate in its continuation by seeking the doctor's expertise. As we as patients do not have the same capacity as our institutions — and in turn other experts — to evaluate our doctors, we generally trust the institutional cadre in order to dispense with the need to find alternative means to evaluate the doctor's expertise; when this is insufficient we also rely on other means (patient groups, the Internet…)

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[164] Goldman, Alvin I. 2018. *"Expertise." Topoi* 37 (1): 3–10. p. 3.
[165] This leads Weber to say that the doctor has never finished "taking care" of his work. Weber, J.-C., 2017. *La consultation*, Presses Universitaires de France. ed. Paris. p. 39.
[166] Here we refer to French legislation, but the author does not know of a healthcare environment in which this is not the case.

The danger, of course, in this trust in our institutions and other means to evaluate expertise is that we may be taking a short cut and forgetting to question the formal or informal organization of that expertise. Therefore we may grow skeptical of this expertise (as well as its organization) when our trust is violated, leading to doubts, anxieties, suspicions[167] that are (at least sometimes) unreasonable and could affect our abilities to have a satisfying doctor-patient relationship (and by extension a trustful relationship with our institutions). However, the reality is that withdrawing trust in our institutions—and our trust in our doctor's expertise—is not feasible for most of us, as our lives depend in many ways on this medical expertise.

The Expert and the Layperson

Goldman[168] and Quast[169] develop the second idea of relational expertise (recognition by those who expertise it is designed to help) by juxtaposing the expert and the layperson.[170] They say that expertise should be defined in reference to what experts can do for us *laypersons* by means of this special knowledge and/or skill (thus showing us the social contribution that the expert brings to the table). When we place trust in this expertise, we do so because we trust in this person with respect to a specific range of action in which they have explicit responsibility.[171] We therefore expect that the doctor will use this expertise to fulfill his professional responsibility both to "do no harm" and to "facilitate his patient's recovery or management of illness to the best of his ability."[172]

However like with the problem of evaluating expertise, how can so-called laypersons identify who is the superior expert compared to others? This is the conundrum in which many patients face today in what is despairingly called "medical nomadism." If we as patients have the right to choose (and to change) our healthcare providers, deciding whom to trust for medical care when we do not have the same kind of knowledge, resources, or networks as doctors themselves remains problematic. Should we rely on the

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[167] O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press. p. 122

[168] Goldman, Alvin I. 2018. *Expertise. Topoi* 37 (1): 3–10, p. 4.

[169] Quast, Christian. 2018. *Expertise: A Practical Explication. Topoi* 37 (1): 11–27. p. 16

[170] While this dichotomy can be criticized for demarcating an artificial line between the two different actors, in the doctor-patient relationship we believe this dichotomy does continue to have relevance because of the obligation of the expert to dispose of prescriptions in the medical act (i.e. patients cannot prescribe medication on their own).

[171] O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press., p. 13

[172] The role identified by Parsons as the doctor's responsibility. Parsons, Talcott. 1968. *The Social System*. Free Press. p. 447

advice of other patients? Of our families? Of patient associations? Of patient experts? Of the Internet and "rankings" of physicians? If we have choice, we do not really have the means to make a fully informed choice, and for that reason we continue to rely on those we deem trustworthy, such as doctors, our families, or patient associations, to help us in our choice, but still our choice still remains an imperfect one.[173]

Seeing expertise in reference to what experts can do us for (us) laypersons shows us a problem inherent in our current conceptions of medical expertise today. If we do not at first question the institution that made the expertise available to us, our criticism changes when confronted with a situation in which we are led to question this expertise. If we take epilepsy, where one third of patients are refractory, then we can understand their frustration that despite all of their physician's expertise, doctors are neither able to cure them of their epilepsy nor even to stop their seizures. How can patients have full trust in medical expertise when doctors are neither able to explain, predict, or treat seizures, especially when these same doctors cannot explain why a treatment works or does not work, and why it could work on one person and not on the next person? The only resource left to patients in these situations (in this long-lasting medical experimentation phase) is to hope that these treatments will one day be effective, or that the lucky ticket (the effective combination of treatments) will be found by the doctor. As a result, they may choose to place their trust in one specialist, hunt around for other specialists, or try out alternative treatments, and they will likely at some point try out all three possibilities. What we can see from these actions is that trust in expertise from the patient's point of view is tied to a certain result (such as stopping seizures). If doctors are unable to produce these results for the patients, their expertise will (likely) be questioned at some stage, because it puts into question this dichotomy between laypersons/experts and their ability to provide some kind of special knowledge or skill.

We have clarified that the expertise of the doctor is evaluated for their knowledge and skill by the institutions that serve us, and indirectly by the people (who seek the healthcare service via these institutions). We can understand that there is a growing mistrust of those institutions which serve us, if in return, the people directed to serve us cannot really do so to our satisfaction (i.e. curing us of chronic disease). Relying on hope, or the "lucky ticket" is space of considerable uncertainty, for the patient, and for the

[173] Parsons already highlighted this difficulty in his book by saying that one of the disabilities of the layman is his incapability to judge technical qualifications. Parsons, Talcott. 1968. *The Social System*. Free Press. p. 441.

doctor, and gives us none of the comfort of the promise of modern medicine to cure us of disease altogether.

Patient Expertise

We will now turn to the patient and their ability to bring individual expertise to the medical encounter. Unlike the doctor, the patient does not have medical knowledge gained from academic studies about the disease (unless they went to medical school), but from living with the disease. The patient's expertise is therefore directly derived from experience with the disease. By experience, we mean the corporal and existential experience gained from "discovering" and then "living with the illness" which is necessarily individual. The patient's experience of disease is linked to the individual body and thus they can be the only person living this experience; although there are some exceptions to this idea, such as the loss of consciousness during epileptic seizures.[174]

This experience of disease, however, is not related to the healthcare act until the patient decides to bring her complaint to her doctor[175]; thus it exists in a temporality before the medical encounter, and (once he leaves the doctor's office) in a temporality after the medical encounter. However, once starting treatment, the disease is evaluated by the outside expert (the doctor), and it is at this point that the individual's experience of the disease is expected to coordinate in some ways with the physician's expertise to enable a diagnosis and a treatment plan. It is also at this point that the patient will also gain knowledge tying individual experience of disease to the theory of disease from a biomedical perspective. This is temporality of risk, as the explanation concerning the disease from a biomedical perspective has more consistency (is easier to explain) than the individual experience of the disease,[176] which means at this point that the experience of the disease lived by the person could be diminished by both the doctor and the person who lives the disease due to overpowering of this (more convincing) narrative.

However, once this encounter is over, the patient goes out into society with the disease. It is expected in patient empowerment terms that the patient will now both have a

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[174] The curious thing about epilepsy is that many patients, by losing consciousness during seizures, do not "experience" their disease, and thus the "experience" of epilepsy is largely lived by their entourage.
[175] Pierron calls this person who suffers before seeking medical expertise, or the decision not to seek medical expertise, the "non patient." Pierron, Jean-Philippe. *Patient, patient expert et patient citoyen. Les conflits de valeurs dans le monde à la portée de l'humain malade.* In *Les valeurs du soin. Enjeux éthiques, économiques et politiques*, Paris, Seli Arslan, 2018. p. 80.
[176] *Ibid.*, p. 77

biomedical knowledge of the disease (a diagnosis and a treatment provided by the healthcare provider) and a special, individual knowledge derived from her own experience of the disease and of the treatment plan. It is unclear, however, at what point this patient "experience" becomes "expertise" in patient empowerment terms.

We propose that from the biomedical perspective as we often speak of "experience" of disease in the first stage (before medical involvement, or outside medical involvement), and "expertise" when the chronic disease has been "treated" (due to medical involvement) and the disease is said to be "managed" by the patient, that this "experience" sometimes becomes "expertise" after having gone through a certain medical filtering of the individual's experience, thus tying it directly to the medical act, the doctor's expertise, and disease nosology. From this perspective, it seems logical that most definitions of patient empowerment consider it as a process taking place within the confines of the doctor-patient relationship.

However, the period between when the patient has a diagnosis/treatment in hand, and at what point she transforms this individual experience (of both the disease and the treatment in her life) into expertise remains unclear as there is no specific time period in which this experience becomes expertise. Unlike the doctor, who undergoes a certification process to validate expertise, the patient does not have any means to validate this expertise, unless it is by healthcare institutions seeking to measure it. Despite this lack of clarity, what this formulation suggests is that patient expertise is formalized and conceived for the healthcare context, not necessarily by or for the patient. It is also likely because of this that there will be a variation between what patients consider their expertise and what healthcare institutions measure as the patient's expertise.

Having clarified that patient expertise is formalized through the medical act, let us now return to the doctor-patient relationship. In an ideal, all of this knowledge (the individual experience or expertise of the patient and the knowledge gained from the healthcare provider, as well as from other sources such as patient associations and the Internet) will coordinate and help the patient live with the disease, through a personalized treatment plan developed by the patient and the doctor. While we can envisage how this individual, interrelated knowledge could potentially help the patient to understand and therefore live with the illness, we are also interested in how the patient's expertise can help the doctor make a more personalized treatment plan (Biomedical Claim 3).

Institutional Recognition of Patient Expertise

As we have stated, unlike the doctor, there is no authority regulating the expertise of the patient. It is encouraged in our institutions that the patient becomes an expert of disease management, all the while providing limited means to recognize this expertise. The patient is thus not given the same kind of institutional cadre in which to evaluate and recognize expertise from a relational point of view, or at the very least not by the same standards or rigor as the doctor. There is no difficulty here if we consider that the patient will use their expertise to manage the disease in their own way, but this is not usually how patient empowerment is formulated (Biomedical Claim 4).

It will be useful to demarcate the three levels in which patient expertise has been mobilized in healthcare to clarify what specifically we are seeking in this discussion. In the first place, patient expertise has been mobilized institutionally (inside the system), most notably with the so-called patient expert programs. Secondly, patient expertise has been solicited through patient groups (which represents expertise outside of the medical system, but also has inroads into the system). And thirdly — and the most important to our project — is the idea that patients bring some kind of special expertise to the "normal" encounter with their physician, which is again expertise inside and outside of the system, as the empowered patient is thought to mobilize this expertise in the medical encounter but also to manage the disease outside of the medical encounter.

In terms of the institutional cadre, we are increasingly experimenting with institutionalizing the expertise of patients through patient expert programs in medical schools and even in hospitals. It is thought that these programs will somehow reverse this asymmetrical relationship as these "expert patients" become the teachers to other patients and to future doctors. Before applauding this idea, we should ask who these patients are and what special expertise (compared to other patients) do they bring. In other words, what relationship do they have to the structure when they become part of the institution, receive training, and even a salary? And what are the vested interests behind such programs, or in other words, which patients do doctors and institutions choose as "experts?" They are unlikely to be those who disagree with the doctor's treatment plan, or with medication prescribed by their doctors. They are also likely to be those who have had good outcomes with their medication. They are therefore most likely a "special" cohort rather than necessarily a reflection of the general patient population. They are also likely to be what doctors and institutions think of as the "good patients" who adhere to medication as prescribed and that have been lucky enough to have good outcomes with their treatment

(following the biomedical model), or those who present special skills seen as a benefit to the institution (such as those who actively participate in patient groups). Thus their expertise is mostly linked to the expertise of the medical act, which is to say they are considered experts given their recognition by the healthcare institution. As Pierron has highlighted, the values privileged with the patient experts include reproducibility, exactitude, and rational demonstration at the service of the efficacy of healthcare institutions.[177] Patient expert programs are a form of relational expertise, recognized via medical expertise and developed to be of service to healthcare institutions.

Thus while patient experts represent a unique cadre from the doctor's expertise, patient experts have the special difficulty of needing to align their expertise with the doctor's expertise, unlike the doctor's validation of expertise that is not dependent on the patient's expertise. They need to coordinate the parts of the experience gained from living their disease and the treatment into teachable knowledge that can be used in the service of the healthcare institution or medical school. The borders of this patient expertise are more fuzzy, as this expertise may stem from expertise outside of the system (i.e. the knowledge the patient gains from their experience), but it ultimately must coordinate or agree with the knowledge given by the healthcare institution in order for it to have recognition and legitimacy inside the healthcare institution.

What about patient groups, which are mostly organized outside of the system but also have networks and coordination within the system? Callon and Rabeharisoa[178] show that patient groups accumulate expertise through problematization, enabling them to acquire a "primitive accumulation of knowledge." This expertise is highly "localized"[179] in that it relies on individual and local experiences of fellow patients. It becomes collective knowledge once processed. The knowledge — gathered from the experience of their members — allows patient groups to counter the expert knowledge of the expert doctor if different and therefore to become "a producer of information and knowledge"[180] allowing

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[177] *Ibid.*, p. 82.
[178] Callon, Michel, and Vololona Rabeharisoa. 2008. *The Growing Engagement of Emergent Concerned Groups in Political and Economic Life: Lessons from the French Association of Neuromuscular Disease Patients.* Science, Technology, & Human Values 33 (2): 230–61. p. 239.
[179] Beck, Stefan. 2015. *The Problem of Expertise: From Experience to Skilful Practices to Expertise. Ecological and Pragmatist Perspectives.* European Journal of Pragmatism and American Philosophy VII (1).
[180] Callon, Michel, and Vololona Rabeharisoa. 2008. *The Growing Engagement of Emergent Concerned Groups in Political and Economic Life: Lessons from the French Association of Neuromuscular Disease Patients.* Science, Technology, & Human Values 33 (2): 230–61. p. 239.

them entry into "research collectives."[181] However, this process to become socialized in institutional networks often involves filling a void in existing medical knowledge, and then integrating this new knowledge into the system. Using patient group's expertise in this way is therefore not in conflict with the physician and does not produce an upheaval in the system. It is complementary and coordinated with the expertise of the institution, as in patient expert programs. In both patient expert programs and in patient groups, this knowledge may be originally sourced from outside the system, but it gradually finds inroads into the system once recognized. In addition, it must be questioned if, in the process of transforming this individual knowledge into collective action through work with healthcare institutions, to what extent it still is a representation of individual patients' experiences.

On the other hand, patient groups also develop and use their expertise outside the system, notably by helping individual patients to navigate the healthcare system and their social and professional life with chronic disease. These groups not only are able to give emotional support and information to other patients and their families, but they also accumulate knowledge about the disease, the healthcare organization around the disease, and individual narratives of medication side-effects, social impacts, and the disease course, which is used in outside networks.

Thus patient groups have the means to provide expertise both in and outside the system; however, it must also be recognized that the groups, as increasingly important political forces, are always looking into the system with an eye for improving patient care and advocating for research around their disease of interest. Their focus is thus halfway in (toward reform of healthcare institutions) and halfway outside (to provide additional or complementary patient support) to the healthcare system in place. While their expertise may provide a challenge to healthcare workers in their relationships with patients (as patients come to the encounter with conflicting information), advocacy for patients becoming more informed through such structures would seem to be a desirable trait, at least in patient empowerment terms. However, the potential conflict between the differing expertise (that of the doctor, that of the patient) has not really been resolved. We will discuss more this idea in Biomedical Claim 4, but we will also highlight some of these challenges now.

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[181] *Ibid.*, p. 242

The Expertise of the Patient in the Consultation

The most interesting aspect of patient expertise for our project is the third idea: the idea that the average patient brings expertise to her meeting with the doctor, which helps the doctor prescribe a more personalized healthcare plan, and that the patient, once outside of the doctor's office, has a certain expertise to be able to handle living with the disease. Thus, there are several kinds of expertise identified here for the so-called "empowered" patient. The first are the two kinds of expertise mobilized in the clinical encounter: that of the doctor, and that of the patient, that should be mobilized to develop the healthcare plan (Biomedical Claim 3). The third expertise is that which is mobilized outside of the clinical encounter, by the patient, in their daily life with the disease. This third expertise could be the same or different from that which is mobilized in the clinical encounter. In the case of the clinical encounter, does this expertise compete with the expertise of the doctor in the clinical encounter? And what exactly is this expertise, and how will it be mobilized? Shall we assume in the formulation of patient expertise that doctors become the laypersons and patients the experts?

A key question to ask in this space for patient expertise is the question of recognition, but in this case recognition by the healthcare provider. If patients bring expert knowledge to the encounter with the doctor that does not mean that the doctor is willing or able to integrate these findings into the treatment plan. Patient empowerment programs see great possibilities in two concurrent actions: 1) patients becoming experts of their individual disease and 2) integrating that knowledge into the healthcare plan. However, for that to occur, it is first necessary that the doctor accepts this expertise as valuable (Biomedical Claim 2) but also that she is able to integrate this knowledge into the healthcare plan (Biomedical Claim 3). This is not only a question of power relations, but also the question of what is valuable information for the healthcare provider (as we have already partly seen at the diagnostic stage). Here is one example of this difficulty for both the patient and for the doctor from my research:

> *A 45-year-old patient comes to see an epilepsy specialist. She has refractory epilepsy, and quite a high number of seizures, which limit her capacity to work but also to remember her medication. The doctor has followed this patient for several years. They discuss in depth about how many seizures she has had in the past 6 months so that the doctor can get a fairly accurate idea of whether the treatment plan is working better than past attempts.*
>
> *Finally, he thinks he "understands" that although the patient says she is fine with her medication, she is having a large number of seizures, affecting her ability to*

> *engage in what she enjoys. He therefore recommends her to change her treatment plan. The patient agrees, reluctantly. They finish the meeting, and just as the doctor shakes the patient's hand, she says, "Doctor, I wanted to tell you, I am now in a singing group and it does me a lot of good."*
>
> *"OK," the doctor says, "I will add it to your patient file."*

There are several issues here. The first is that the doctor is following a protocol, or what he calls "practically a police investigation" to understand what has been happening since the last time he saw his patient. The patient, in turn, answers as best she can, but her perspective is necessarily different from his perspective, as he is seeking understanding about adherence and treatment effectiveness through the patient's narrative, while the patient is speaking through her biography (i.e. her life with epilepsy). Due to her memory problems, it is difficult for both sides to get an accurate idea of whether the treatment is working or not, especially as she cannot remember when her seizures occur and she needs others to witness these seizures to be able to record them. The patient is bringing her expertise of her seizures, necessarily her own, to the encounter, even if this expertise is fragmented by her disease. In patient empowerment terms under the biomedical model, she is bringing needed expertise to help the doctor make a personalized decision concerning her treatment. The knowledge helps him realize that the treatment plan might not be effective and therefore he suggests a new one. From this point of view, we can say that Claim 3 of the Biomedical Model has been achieved.

However, another expertise comes to play at the end of the consultation, when the patient decides to introduce an expertise which she believes helps her with her epilepsy, in her case, singing. While studies on epilepsy have shown some correlations between stress reduction and seizures[182] there is no strong proof from the biomedical perspective that this complementary "treatment" or even "lifestyle choice" has some correlation in seizure reduction. While the doctor could suppose that this gives her a social activity, which may also help in stress reduction, and because of this singing could be beneficial in reducing her seizures, the linkage between these factors is not straightforward from a biomedical standpoint. Therefore, the doctor responds by saying, *"I will add it to your patient file,"* but does not take any further steps. Indeed, how could the doctor integrate this information into the personalized healthcare plan? It may help him to have a more global knowledge of

[182] Galtrey, Clare M, Marco Mula, and Hannah R Cock. 2016. *Stress and Epilepsy: Fact or Fiction, and What Can We Do about It?* Practical Neurology 16 (4): 270–78.

the person he is treating (in the biopsychosocial/mutual investment company perspective), but it is difficult to imagine how this will affect his prescription. Indeed, there seems to be no other action plan other than adding the information to the patient file.

Another interesting thing about this final exchange is its temporality: the fact that the patient decides to introduce the information about her singing when effectively, the consultation has reached its end and the prescription is in her hands. If the doctor does not have any action plan other than putting this in the patient file, the patient also seems to hesitate in giving this information to the doctor during the clinical encounter, either from fear that this information may not be well-received, or like the doctor, or "not quite sure" if this information is relevant to her treatment. Thus how this individual expertise will actually be mobilized in the doctor-patient relationship remains unclear. Even if the doctor decided to put into place a control by not changing her medication and seeing if the seizures increased or decreased due to this activity, this small case study is unlikely to be generalizable to other patients. It might also be questioned, as many other factors of daily life might also affect the frequency of her seizures. Therefore, it seems unlikely that this particular expertise will enable the doctor to make a better treatment plan for this patient, showing both the patient's and the doctor's hesitation for the place of this information in the encounter.

Therefore, it remains challenging — both for the patient and for the doctor — to find a place for patient expertise that is not coordinated with biomedical understandings of disease. Although it may be physically input into the patient file, this does not mean that it will be further mobilized in the treatment plan, unless the healthcare provider herself sees a link between this activity and the disease (such as proposed by Balint and Engel's models, but also unresolved by them). From the viewpoint of the healthcare practitioner, this information will need to be seen as valuable from their (biomedical) perspective to be able to integrate it into the personalized treatment plan.

For the patient, however, it will also need to be shown as valuable in order to share this information with the healthcare provider. After all, does the patient value her relationship with her doctor, and therefore decide to share this information to permit a better treatment plan, or does she value the possibility to be able to care for herself outside of the doctor's office, and is sharing this information a means of showing her own participation in her seizure control? If doctors from the biomedical perspective have doubts about the value of this information, patients doubt it too. They may also hesitate to share

this information in the clinical encounter because they see it as their personal domain (as Case Study 1 highlighted).

Patient Expertise Outside of the Consultation

The second issue here is how the patient will be able to mobilize her expertise outside of the clinical encounter. By "outside" we mean all of the spaces not integrated into direct healthcare decision making, including but not limited to private and family life, employment or leisure activities, and activities involving other patients. Therefore, we are referring to spaces that could influence future interactions with the doctor, such as patient association activities in which information could be shared, but which remain in the domain of the patient's private life. According to Beauchamp and Childress, this domain consists in respectful action from the part of the healthcare provider and consists in non-interference in the other's personal affairs.[183]

In the example of singing, this patient has found a means of treating her individual disease. Whether this experience can and should be more generalized is, however, questionable. This expertise will most likely find its place in this patient's individual life, but it is possible (if the patient chooses) that this information may also find its way to other outside spaces, such as patient groups, Internet forums, etc. which may prove valuable to other patients. Therefore, the question to ask would be the extent in which such information has a place inside the clinical encounter to help the healthcare practioner make a personalized healthcare plan, but also to permit the space for patients to find individual, expert ways of living with their disease.

Whereas in the clinical encounter, it is both up to the patient to share this information and up to practioner to use it (if the doctor finds it valuable), outside of the consultation room the patient is free to use this expertise as she wishes. It is no problem for certain types of expertise to be used outside of the clinical encounter; however, it does not follow that Biomedical Claim 3 has been fully achieved, as this expertise has not been deemed useful in the treatment plan. Therefore the place for other kinds of expertise not adapted to the biomedical model, or rather not proven in biomedical studies, continues to have an uncertain place, both for doctor and for patient. While it may help the doctor to know better the patient, it will not necessarily affect the personalized treatment plan.

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[183] Beauchamp, Tom L., and James F. Childress. 2001. *Principles of Biomedical Ethics*. 5th ed. New York, N.Y: Oxford University Press. p. 63

Therefore, while Biomedical Claim 3 has potential, its limits within the current way medicine is practiced — and valuable information filtered by both doctor and patient — needs to be recognized.

1.5.4. Patient Satisfaction, Adherence, and Outcomes

The fourth idea, that the patient will be more satisfied in the medical encounter due to greater participation, and will therefore follow the treatment plan, which will lead to a better healthcare outcome, is full of promise and difficulties for those seeking to secure healthcare outcomes on the ground. There are three correlations, one leading to the other, which continue to baffle. We must first ask what it means for the patient to be satisfied in the clinical encounter; then what being satisfied has to do with following the treatment plan; and finally how these two factors work together to enable a better healthcare outcome.

Patient Satisfaction

To unravel the first complexity, what does it mean for a patient to be satisfied in the clinical encounter? Patient satisfaction measures have become an increasingly attractive way for healthcare providers to measure of the quality of care from the patient's perspective.[184] The advantage is that it gives patients a voice in healthcare evaluations; however, using satisfaction to understand if patients are getting what they want and getting what they need from their healthcare provider remains challenging. While definitions of patient satisfaction are diverse, they often suggest a correlation between the patient's *expectations* and their *experience*.[185]

Patients have a diversity of reasons to be satisfied or unsatisfied in the clinical encounter based upon their expectations and whether or not these expectations have been met. We can assume that it could be because the doctor provided a treatment plan that worked for them; it could be because he was friendly and seemed to treat him like a "human being"; however, it could also simply be because the doctor gave the patient what they wanted. If we use satisfaction as a criterion for assessing patient empowerment, we will have to take stock of these diverse reasons for the patient to be satisfied and the

[184] Van Campen, C, Sixma, H, Friele D., Kerssens, J. and Peters, L. 1995. *Quality of Care and Patient Satisfaction: A Review of Measuring Instruments.* Medical Care Research and Review 52 (1). p. 110
[185] *Ibid.*, p. 127

ramifications for that choice. For instance, if we think that patients will be satisfied and thus more adherent, because the doctor gave the patient the prescription wanted, then we are choosing above all a consumerist model of the patient-doctor relationship. We will not be taking into account whether this prescription was better for the patient (and the fact that it could even be harmful). On the other hand, if patients are satisfied with the medical act because the doctor was "nice," it does not follow that they walked away with an appropriate treatment plan, either.

Satisfaction and Treatment Plans

The most promising formulation is in saying that patients were satisfied because they received a treatment plan that worked for them. However, we will in turn need to ask, "it worked in what context and when?" To use the example of epilepsy, did the new treatment plan reduce or stop their seizures (the definition of a good treatment plan for the doctor), or merely give patients the impression after the consultation that it would reduce the seizures (because the treatment plan changed)? This leads us to ask in what temporality the patient was satisfied: if the patient asked to change her anti-epileptic medication, and it worked for a few weeks, then presumably she was satisfied at that point in time. However, if it was the week after, when she had several seizures, the evaluation of satisfaction could be completely different. Thus, while promising as a way to give patients more voice, patient satisfaction remains an imperfect formulation to understand healthcare outcomes.

Doctor-Patient Communication

It is generally recognized, however, that physicians play a large role in patient satisfaction as they are the main point of communication with patients and the main actors of the healthcare institution. According to one study, the patient-provider relationship had the greatest influence on overall satisfaction in healthcare, following by wait times, the environment, and patient education.[186] However again, the reasons for patient satisfaction with their healthcare provider are diverse and variable. One study for instance showed that patient satisfaction among inpatient adults was linked to the physician's specialty and

[186] Famiglietti, Robin M., Emily C. Neal, Timothy J. Edwards, Pamela K. Allen, and Thomas A. Buchholz. 2013. *Determinants of Patient Satisfaction During Receipt of Radiation Therapy.* International Journal of Radiation Oncology*Biology*Physics 87 (1): 148–52. p. 148.

age.[187] The study concludes that patients link the older age of the doctor with more expertise and were more satisfied as a result. Patients also linked satisfaction with specialties, with surgeons ranking above general practioners.[188] Patients were also more "satisfied" when the medical procedure was linked to a joyous event (such as a birth) or the termination of a problem (such as removal of a tumor during surgery) compared to when doctors provided a long-term treatment plan for the patient, treating but not curing them.[189] What these kinds of results may show us is our unconscious bias for certain doctors,[190] but also our inability to assess expertise from a layman's point of view.[191] Patients rely on imperfect indicators to gage whether the doctor is competent and the healthcare service satisfactory such as the more specialized practice or the number of years of practice, good outcomes such as taking out a tumor, or the age of the physician.

From the perspective of patient empowerment, patient satisfaction also does not give us much means for action other than if we use these results to favor certain doctors, which would be both discriminatory as well as (potentially) harmful for the patient. Therefore, all that patient satisfaction shows us is that (again) the patient may not be adequately informed of a means to evaluate expertise, leading to bias, but also showing a limited potential for agency by the patient in the evaluation of expertise.

However, in the perspective of patient empowerment according to Biomedical Claim 4, we are saying that patients will be more satisfied because they participated in their healthcare plan, because doctors helped them (or at least permitted them), and because the doctor developed a treatment plan with the patient. Logically, if all of these steps followed the other, the patient would be satisfied and ready to follow the treatment plan. However, as we have seen, all of these suppositions are problematic for the patient. Patients have to want/be able to leave the sick role; doctors have to be ready to support patients; and the doctor has to be able to plan the treatment plan with the patient's input (which is sometimes possible, but not always easy given the differing expertise or the uncertainty of where patient expertise fits in).

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[187] Chen, J Gene, Baiming Zou, and Jonathan Shuster. 2017. *Relationship Between Patient Satisfaction And Physician Characteristics.* Journal of Patient Experience 4 (4). p. 177.
[188] *Ibid*. p. 179.
[189] *Ibid*. p. 182.
[190] *Ibid*. p. 182.
[191] Another factor could be religious belief. Fainzang has for instance shown that patients according to their religious belief may prefer a specialist over a generalist, and that their level of trust in that person may change depending on religious belief. See: Fainzang, S., 2001. *Médicaments et société: le patient, le médecin et l'ordonnance*, 1re éd. ed, Collection « Ethnologies-controverses. » Presses Universitaires de France, Paris. p. 106-147.

Patient Satisfaction and Healthcare Outcomes

However, assuming that all of these factors harmonize to create a situation in which the patient has a say in the treatment plan, can we in turn say that the patient will be satisfied? Not necessarily. As we saw from research on the factors influencing patient satisfaction, one of the indicators of patient satisfaction was whether the doctor was able to cure the patient. As patient empowerment has been proposed in particular for chronic disease patients, even with full participation by the patient in all of the steps, we cannot assume that patients will be necessarily be satisfied, because they will not necessarily have the outcome they are seeking (which is above all a cure). However, many studies have found a linkage between patient satisfaction with their healthcare provider and adherence to medication. In particular, good physician communication (a factor influencing patient satisfaction) is positively correlated with patient adherence.[192] However, the World Health Organization identifies many other factors influencing adherence: (1) social and economic factors (2) the healthcare team/system (3) the characteristics of the disease (4) disease therapies and (5) patient-related factors.[193] If the patient-doctor relationship is an important part of this list, it is not the (only) factor that influences adherence; while the doctor may stimulate or encourage other factors by taking into consideration patients in their globality, patients do not take their medication for a large variety of reasons. These factors may also change over time. While the healthcare provider may be able to take into consideration all of these factors when devising the treatment plan (such as choosing the cheapest medication for the patient because of high costs[194] or choosing the option with the least side effects), a large part of why the patient will decide to adhere the doctor will not have any influence over. Thus placing responsibility for adherence in the doctor-patient relationship is still too narrow a focus to understand adherence, let alone patient empowerment.

Let us now proceed with our investigation by seeing if there is a relationship between patient satisfaction and clinical outcomes. Although satisfied patients are more adherent to physician recommendations and in turn more loyal to these physicians, the correlation between patient satisfaction and clinical outcomes is mixed. Some studies show

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[192] Haskard Zolnierek, Kelly B., and M Robin DiMatteo. 2009. *Physician Communication and Patient Adherence to Treatment: A Meta-Analysis.* Medical Care 47 (8). p. 827.
[193] World Health Organization, ed. 2003. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva.
[194] A common factor that is taken into consideration in China in prescriptions.

a positive correlation, while others show no correlation or even an inverse correlation.[195] In a study conducted in the United States, for instance, higher patient satisfaction was associated with less emergency department use but also with greater inpatient use, higher overall healthcare and prescription drug expenditures, and even increased mortality.[196] This can be partly explained by the fact that satisfaction has been correlated with the extent in which physicians fulfill patient expectations. If the patient expects unnecessary and costly treatments, and the physician fulfills this request, then the patient may be more satisfied, but the healthcare system is worse off (and so arguably, is the patient).[197] Thus, the link between satisfaction and good healthcare outcomes is not sufficient to understand clinical outcomes.

Adherence and Clinical Outcomes

There does appear to be a link between adherence[198] and clinical outcomes, from the biomedical point of view.[199] If the patient follows the treatment plan devised by the doctor, and if this treatment plan is the right one (from a biomedical point of view), it follows that there will be better outcomes than in not following the treatment plan. By not following the treatment plan, we mean either doing nothing (which could worsen the disease) or by irregularly taking medication, which could be worse than doing nothing in some cases (irregular use of antibiotics has shown us this problem).

More interesting to our project than this biomedical link is the correlation between adherence and clinical outcomes for patients themselves, based upon their own experience of living with the disease and the treatment. To take the example of epilepsy, a clear biomedical link has been established between seizures and non-adherence to medication. Non-adherence or imperfect adherence to anti-epileptic medication (AEDs) can lead to

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[195] Kennedy, Gregory D., Sarah E. Tevis, and K. Craig Kent. 2014. *Is There a Relationship Between Patient Satisfaction and Favorable Outcomes?*: Annals of Surgery 260 (4). p. 596.

[196] Fenton, Joshua J. 2012. *The Cost of Satisfaction: A National Study of Patient Satisfaction, Health Care Utilization, Expenditures, and Mortality.* Archives of Internal Medicine 172 (5). P. 405.

[197] *Ibid*. p. 409.

[198] In English the word "adherence" is preferred to "compliance" to emphasize that patients will adhere to clinical outcomes in which they participate instead of those in which they comply (it has therefore been argued therefore to take place within the empowerment paradigm, rather than paternalistic viewpoint). However, we question if this choice of wording has actually changed something for patients themselves on the ground. For the distinction between adherence and compliance, see: McAllister, M., Dunn, G., Payne, K., Davies, L., Todd, C., 2012. *Patient empowerment: The need to consider it as a measurable patient-reported outcome for chronic conditions*. BMC Health Serv Res 12, 157.

[199] For epilepsy and adherence, see for example: Ernawati, Iin, Wardah Rahmatul Islamiyah, and Sumarno -. 2018. *How to Improve Clinical Outcome of Epileptic Seizure Control Based on Medication Adherence? A Literature Review.* Open Access Macedonian Journal of Medical Sciences 6 (6).

seizures,[200] which increases the risk of self-harm, harming others, and even sudden death. However, this perspective also largely correlates with the patient's perspective according to my research. Epilepsy patients often say, "*I had a seizure today…but it's because I forget to take my medication."* Although they have been taught by the physician this link, they have also experienced it themselves, which made the link have epistemic authority for the person experiencing it. In other words, some patients link adherence with treatment outcomes from their experience.

That said, the link may not as straightforward for other chronic diseases, nor is it altogether straightforward for all epilepsy patients. Patients that forget to take their medication, and have no seizures, for instance, may start to wonder if the medication actually has an influence on their seizures and start to question the treatment plan and the expert behind it. Thus for patients whose experience concords with biomedical knowledge, Biomedical Claim 4 holds great potential, but it is unlikely to be a useful means to assess those patients who have different experiences, such as those patients who do not regularly take their medication yet have no seizures. This situation could also put into doubt their trust in the expertise of their doctor and thus their willingness to be adherent to the treatment plan, even if they participated in its elaboration.

However, even if the link between adherence and clinical outcomes is established, we should still question it from the patient's perspective, which is to say, if clinical outcomes (from the biomedical perspective) are necessarily the same outcomes the patient is seeking. In the case of epilepsy, while it is reasonable to assume that patients wish to avoid seizures, if medication adherence is linked to side effects such as excessive fatigue (a major side effect of epilepsy medication), at times it could be better not to adhere from the patient's perspective while there is no value in not adhering from the biomedical perspective.

This suggests a value judgment linking adherence to patient outcomes that will need to be investigated. If the formulation of "action" for the patient means giving a certain autonomy of choice to the patient from an ethical standpoint (the right to choose what is right for them) in recognition of diverse needs and values, under this formulation, the choice may still be taken to be "bad" by the healthcare provider if it involves non-adherence to the treatment plan. This suggests that the choice is not really our choice (as

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[200] Cramer, Joyce A, Marc Glassman, and Vincent Rienzi. 2002. *The Relationship between Poor Medication Compliance and Seizures.* Epilepsy & Behavior 3 (4). p. 338.

patients) at all. It is the doctor's. As healthcare systems allow access to healthcare, and make healthcare providers responsible for the treatment plans of their patients, we (as a society) in turn expect a certain amount of patient responsibility in the use of these resources.[201] In addition, it is assumed that the doctor's advice is (necessarily) in the best interests of the patient (in the logic of "do no harm").

Patients, however, do not adhere to medication for a variety of reasons, as outlined by the World Health Organization's list. In addition, we are questioning as societies more and more if the choice not to adhere is so bad after all, given the often heavy burden — both psychologically and physically — of pharmaceutical solutions. Therefore, even if patients are satisfied with their healthcare provider and adequately informed through good patient-doctor communication, it does not follow that they will necessarily choose to follow their treatment plan, nor that this is the right decision for them, even if they participate in the decision making process. They may explore other options, other healthcare providers, and other lifestyles, even while enjoying a satisfying relationship with their healthcare provider for the expertise brought to the encounter. From an ethical point of view, this is the patient's right even though it may be bad for them (in terms of hospitalizations, etc.).

Therefore, in Biomedical Claim 4, by linking adherence with "being active" we are suggesting that the patient will act for his own good, but what we actually mean is "good" for others (including economic actors). Being good is thus linked to the society's good in terms of cost reduction and better healthcare outcomes, not necessarily to our own, individual good. This linkage suggests that under the biomedical formulation of patient empowerment, the society's good may take precedence, even while we advocate for the patient's right to be empowered from an ethical point of view.

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[201] Bateman, S., 2001. *La responsabilité médicale aux frontières de l'activité thérapeutique Le cas de l'assistance médicale à la procréation*, in: *Juger La Vie: Les Choix Médicaux En Matière de Procréation*, Cahiers Libres. La Découverte, Paris. p. 114.

Preliminary Conclusion

The series of claims in the biomedical model face a number of difficulties, notably by suggesting a sequential chain of events: an activated patient works with the doctor to define a personalized healthcare plan, leading to patient satisfaction and adherence. It does not take into account if the sick role has really changed, of the vulnerability and dependence that many patients face. Thus, it does not adequately question the first premise which leads to all of the others: what participation exactly are patients seeking?

In the meantime, while patient expertise is championed, its potential for inclusion in the biomedical model of disease remains full of difficulties both for the patient and for the healthcare provider. There is the problem of differing views of patient empowerment; the question of whether patient empowerment can help the doctor as well as the patient; and whether healthcare institutions have adapted to allow for the additional time for the so-called empowerment patient. There is also the problem of the legitimacy of expertise, how it helps the (expert) doctor in his craft, and whether patients actually want to give all necessary information to the healthcare provider.

As Althusser has shown, specific socio-economic structures, such as healthcare,[202] require ideologies in order to function (what he calls *ideological state apparatuses*).[203] When a doctor is recognized as an expert within the healthcare institution, they often reproduce society's dominant ideological patterns.[204] In turn, the discourse through which healthcare professionals communicate their knowledge helps them intervene and control individual behaviors, albeit often unintentionally.[205] What becomes apparent in this discussion of patient empowerment (notably in Biomedical Claim 4) based upon the biomedical model is that an empowered patient is one in line with and harmonized with the doctor's expertise. It suggests that through patient empowerment, what we are seeking is adherence to medication, leading to "good" clinical outcomes from both a biomedical and an economic perspective. Adherence to medication could reflect the patient's perspective, but it will not necessarily do so. As such, it is principally the healthcare institutions (and economists) point of view. We propose to define the biomedical view of empowerment

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[202] Althusser did not include healthcare institutions within his list of ideological stated apparatuses, but it has been taken up elsewhere.
[203] Althusser, L., 1970. *Idéologie et appareils idéologiques d'État*. La Pensée.
[204] Waitzkin, H., 1989. *A Critical Theory of Medical Discourse: Ideology, Social Control, and the Processing of Social Context in Medical Encounters*. Journal of Health and Social Behavior 30, p. 224.
[205] Waitzkin claims that there are several reasons in which doctors may perpetuate such social structures, including their relative status in society, their medical training, the limits of the doctor's intervention to be able to assist to the patient, etc. *Ibid.*, p. 226-227.

therefore as: *a process to empower the patient in order to encourage better healthcare outcomes through adherence.* If the patient is empowered, they are empowered in order to respond to this need, which is not (necessarily, or at least not always) their own.

This view of patient empowerment is unsatisfactory for our purposes. In the first place, our discussion has shown why patient empowerment from this sequential list continues to be an imperfect methodology to improve clinical outcomes. In addition, from an ethical point of view, it gives little say for the patient. It seems obvious from this discussion that we haven't (yet) asked the patient's opinion or if we have asked for his opinion, we have not (yet) incorporated it in the biomedical model of patient empowerment, which is largely how patient empowerment programs have been designed on the ground. If we want the patient-doctor relationship to be collaborative, if we wish to improve clinical outcomes, we must listen to the patient. For inspiration, let us now complete Oliver Sacks' quotation from the beginning of this chapter:

> *"There is only one cardinal rule: one must always listen to the patient; and by the same token, the cardinal sin is not listening, ignoring. Prior to any and all specific approaches, there must be this general approach, the establishment of a relation, a communication with the patient, so that the patient and the physician understand each other. A relationship, moreover, in which the patient is not entirely passive and compliant, believing and doing what he is told, and taking what is 'ordered'; a relationship, which is essentially, collaborative."*[206]

We have just described a situation in which the patient's perspective has effectively been silenced due to these biomedical claims. Let us now see how patient empowerment has been formulated on the ground.

[206] Sacks, Oliver. 1992. *Migraine*. Rev. and expanded. Berkeley: Univ. of California Press. p. 252.

1.6. Patient Empowerment on the Ground

Patient empowerment has been expressed in various ways and means in our institutions. It was also understood in different ways by patients and healthcare providers themselves. As we have shown, patient empowerment in the 20th century is intimately linked to politics. However, while ethical claims have been used to advocate for political change for patients, they have also been used as a political tool to reinforce the economic reasoning behind patient empowerment. It will be interesting moving forward in our discussion to see how these political claims have been formulated in our institutions due to these diverse political interests. If we identify the civil rights movement, for instance, as the "spark plug" of patient empowerment, this would suggest that patient empowerment started from these fundamental beginnings, and therefore should be "from the ground up." However in reality patient empowerment programs have largely been designed by healthcare providers and institutions themselves, rather than from the patient, due to their own interests and calls for participation. What does this mean for patient empowerment? Is it acceptable to speak for the patient if we keep the patient "in mind" or at the "center" of our healthcare policies, or do we need to incorporate the patient's view directly? As patient empowerment has not been fully achieved, how can we move forward with this idea, and, when we think of ourselves as current (or future) patients, do we even wish to participate in this way?

Therefore, let us now look at some examples of how institutions have conceived, formulated, and put into place patient empowerment in our institutions. Here we will largely focus on the French example. A common formulation of patient empowerment programs in French hospitals are the so-called therapeutic patient education programs, designed to complement the traditional doctor-patient relationship by allowing patients to "undergo training" about their disease. By being initiated and put into place in the institutional cadre (the hospital), patient empowerment programs have been largely designed and put into place by healthcare providers (mainly nurses), and not, as first could be supposed, by patients or patient representatives themselves.[207] This is logical from the standpoint that healthcare institutions have been tasked with the responsibility for patient

[207] They are sometimes co-run with healthcare staff and representatives of patient associations. An example of this is therapeutic patient education for epilepsy patients in Grenoble, where there are some programs run exclusively by nurses, and others by teams of nurses and patient representatives.

care and have the means to put into place these programs (as well as technical staff capable of training patients); however this formulation of patient empowerment has created a number of difficulties for the patient in terms of having a say into the content of these trainings. In the first place, patients have not really exited the propositional attitude (after all, their right is really just a right to say yes or no to the training that has already been designed, even if the program is "personalized" for them).

It can also be said that healthcare providers have two needs[208] in mind in designing these types of programs: the first is the ethical obligation, for patients to participate in a more active way in their healthcare, and to be informed about their disease and their treatment. Another need, however, is for the healthcare organization to invest in programs which can lead to better healthcare outcomes (the biomedical claims). This means that patient empowerment programs have been designed with two — potentially competing needs — in mind. The danger of creating such programs with two conflicting needs is that there is likely to be a choice to be made. The biomedical goal is very persuasive: it would seem to be more important for the patient and for the healthcare provider, at least on the surface, as the end goal is better treatment outcomes. On the other hand, thinking of patients as agents, as beings capable of acting according to their own needs and values, means allowing the space for patients to act against their best interests. This might be bad for the patients, but is also bad for healthcare professionals, leading to potentially bad healthcare outcomes from the biomedical point of view (i.e. non-adherence). It therefore seems likely that the biomedical perspective will take precedence in the design of such programs.

The problem of this preference in the program design is not that they are proposing the biomedical perspective (which has its advantages), but that we are claiming ethical talking points in the promotion of such programs (the patient's right to participate, to be informed, to know their disease, etc.). Not only is this untransparent for the patient, but it does not give the patient a voice into design of these programs. It also does injustice to the patient (more to come in the next section), who is expected to follow these programs but without having any input into their design.

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[208] Here we are referring to Nordenfelt's definition of needs as *"the necessary conditions for the realization of a goal"* as the goal is to have an empowered patient, for a variety of reasons. Nordenfelt, L., 1995. *On the nature of health: an action-theoretic approach,* 2, rev. and enl. ed., Philosophy and medicine. Kluwer, Dordrecht. p. 59

To clarify, we are not discounting the value of these programs for patients: by learning more about their disease and treatment, patients may have better knowledge — and in turn — better expertise, no matter how they (finally) choose to do so. However, as they have not been designed by healthcare providers, we are either not aware of or not prioritizing their needs. Instead, their needs are being understood through the filter of the healthcare provider, which is largely a biomedical view of what are their needs. If we talk of gaining knowledge, then we are talking of the healthcare provider's view of what that this knowledge consists. Skelton has gone as far as to say that these types of programs are a form of disguised paternalism. She claims, "*under the guise of the fashionable rhetoric of 'empowerment' there lurks an older view that 'the professional knows best.' 'Empowerment' is about getting you to come around to a way of behaving that I, the expert, knew in advance was good for you, whilst encouraging you to think that changing your behaviors was your idea in the first place*."[209] Even if this statement can be debated, we need at least to recognize that the way patient empowerment programs have been designed with double, competing needs. If we see these programs as having as a final goal better healthcare outcomes (in the biomedical model), they may be the end goal of the patient as well, but as we have not involved them in the development of such programs, we are speaking through and for them, not with them. From the ethical standpoint, this is a problem, at least for those patients who seek empowerment outside of the biomedical model.

To return to the etymology of the word "em-power", we are still seeing patient empowerment programs being organized as a privilege by healthcare providers. Therefore, the idea is not necessarily — or not only — led by patients, but rather accorded by authorities. While patients can make inroads into the institutions (such as patient groups and patient experts have done), at some point their authority will need to be recognized by an institutional authority to have weight. As we have shown, this formulation remains coherent and feasible as long as the patient's knowledge and desire to participate align with the biomedical model. However, patients — and in turn patient groups — with differing needs or conceptions from the biomedical model will have difficulties to have these needs recognized and/or prioritized. Thus although healthcare institutions may argue for patient empowerment from the ethical perspective, if we take these realities into account, we are

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[209] Skelton, Robert. 1994. *Nursing and Empowerment: Concepts and Strategies.* Journal of Advanced Nursing 19 (3): 415–23., p. 418

not very far from the paternalistic system that argues that the doctor and in turn the society knows what is best for the patient.

Let us now return to the human rights perspective (which in this case is also the feminist perspective). It is also time to be realistic (if not cynical, but with a solution in mind). If we cannot (only) argue for patient empowerment from an ethical point of view (that the patient's rights are paramount), and if the reality is that biomedical needs take precedence, because we ultimately (as a society) wish to decrease healthcare costs, then let us ask how to make this a reality! If we wish for empowerment to be realized on the ground, we will need to take into consideration the wider environment and the actors affecting the patient's ability to act. As I will show with epilepsy, the structural agents that can help us achieve these needs include not only healthcare providers, but also families, other patients, but in a more general and global way, society, which can help or hurt patients' abilities to be empowered. The relational autonomy perspective will help us release the pressure on the unrealistic view of the patient as an autonomous individual, working toward healthcare outcomes. Imposing obligations on these so-called autonomous individuals to become empowered in order to stay adherent, and encouraging doctors to create an enabling environment, has not only made patient empowerment difficult to achieve on the ground but has also placed additional strains on this — already strained — doctor-patient relationship. We need to take into consideration the wider social context and the means in which we can become empowered with the help of others (or disempowered because of others). We will be developing this wider perspective of patient empowerment in subsequent chapters.

Before closing this discussion, we would like to add one more difficulty. In patient empowerment discussions, it is often seen as desirable to have an empowered patient. However, there are some problems with this claim. In the first place, it presumes that patients are disempowered. Is it really for us to say that patients are disempowered, or that they need to become empowered? While we may be claiming that patients that are disempowered have the right to become empowered, by putting patients under the category of disempowered, we are once again making a judgment on their state of being and the desirable qualities that we (as healthcare institutions) wish them to cultivate. We are also saying that patient behavior will need to be changed or supported, or even enhanced for empowerment to occur.

This formulation is both promising and problematic: it is promising as it sees the doctor as an important actor in assisting the patient, but is problematic as it takes away the

agency for the patient to decide what are the desirable qualities they wish to cultivate and the means in which they will cultivate them. In turn, if the patient is disempowered, their participation will be decided and planned by the healthcare provider. This ignores the knowledge and experience the patient brings before the clinical encounter, during the clinical encounter, and after it, which does not necessarily correspond with the doctor's experience and knowledge. In these formulations, it remains difficult to see how we can conceive of patients as capable beings outside of the doctor's office.

We will therefore need a wider empowerment model that takes into perspective the patient's capacities — but not impositions — to act in ways that respect their needs and their values. In the third chapter of this thesis, we will use the capabilities approach (CA) to help us understand and conceptualize patient empowerment from the patient's perspective. It is a theory that develops the capacities *to be* and *to do* but does not impose their functioning. It aligns with the objectives discussed in this chapter to create the space for patients to be active by creating possibilities but not by imposing actions.

In order to finish this section, let us flip the coin on this question. If patient empowerment is "desirable", we cannot presume that it is desirable for everyone. Many patients — and most at some point in the healthcare relationship — will desire not to be active, at least for a certain amount of time. Some patients will never be capable — or desire even if capable — of leaving the sick role. After all, is it not the great luxury of all of us as patients to be able to say to our doctor, "please take care of me?" Even if we wish for participation, in some cases, especially if we have confidence in the doctor's expertise, not participating actively could also mean placing our trust in that professional rather than run around endlessly searching for better experts. Thus, we cannot presume for patients either what it means to be empowered, or when or how patients (and families) will be empowered. What these discussions of patient empowerment bring to us is a problem. We can see that the patient's voice has been largely silenced, discounted, or ignored, both into the vision of patient empowerment and in its formulation on the ground. We maintain that this may be a question of epistemic justice.

1.7. Epistemic Injustice

The English philosopher Miranda Fricker invented the concept of epistemic injustice to mean something done wrong in a person's capacity as a knower.[210] Fricker is interested in social power, namely the capacity of social agents to influence how things go in the world.[211] She distinguishes two types of injustice: in the first case, *testimonial injustice* (a person wronged in their capacity as a giver of knowledge), and in the second case *hermeneutical injustice* (someone wronged in their capacity as a subject of social understanding).[212] Our project investigates both types of injustice, by exploring why patients do not have the capacity as a giver of knowledge in the development and implementation of patient empowerment, as well as why patients have been wronged in their capacities as subjects of social understanding.

1.7.1. Testimonial Injustice

Fricker proposes the concept of testimonial injustice to mean a reduced credibility given to a speaker's assertion by a prejudice of some kind.[213] When using the word testimony, she is not just referring to speech acts, but also other forms of telling such as a hypothesis, suggestions, questions, etc. In daily life, people incorporate a variety of roles in society, including as sources of information and/or as informants. For Fricker, the problem is not that people are one or the other at various times; the injustice comes in a prejudicial situation, i.e. when people are *merely* sources of information rather than informants. This is a problem because being merely a sense of information implies objectification[214] rather than possible contributions to social knowledge. Thus testimonial injustice is inherently a relational matter between a speaker and a listener.

Testimonial injustice can happen in different temporalities: the person's viewpoint for instance may not be taken into account in a speech act after or pre-emptively. This type of injustice often expresses itself through *silence*, such as when the person is simply not

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[210] Fricker, M., 2009. *Epistemic injustice: power and the ethics of knowing*, 1. publ. in paperback. ed. Oxford University Press, Oxford. p. 1
[211] *Ibid.*, p. 7
[212] The concept has further developed through other formulations of epistemic injustice by other researchers; for our analysis, we will only use Fricker's terms to maintain consistency for our project.
[213] *Ibid.*, p. 4
[214] *Ibid.*, p. 132

given a voice to participate.[215] Fricker maintains that an essential feature of personhood is the ability to participate in the spread of knowledge by testimony and to enjoy the respect enshrined in a proper relationship of trust.[216] This form of epistemic injustice is particularly disabling to the person experiencing it as she effectively loses knowledge.[217] The problem with testimonial injustice for the speaker is that it results in self-doubt and lack of confidence. It is quite nasty for the person experiencing it as the person cannot only be silenced but also self-impose this exclusion.

Testimonial Injustice in the Healthcare Field

Applications of Fricker's idea to the healthcare field have been growing in popularity; however, we must express some caution. Because of the implicit and explicit knowledge asymmetry in the doctor-patient relationship,[218] there is a certain amount of epistemic privilege inherent in its structure. We have already discussed how difficult this epistemic privilege makes it for patients to fully participate in partnership with their healthcare provider. However, this is not necessarily a case of injustice, as the doctor is there to bring assistance to the vulnerable person. This is both the role given to the doctor by the healthcare institution, but it is also the one solicited by the patient. Thus the epistemic authority of the doctor in this relationship is to a certain extent expected.

Secondly, in the methods used to diagnose and find the treatment plan in models such as EBM, the process in which the doctor investigates the diseases includes a certain amount of medical objectification that abstracts from patient experience.[219] Part of this involves using the patient's testimony (as a source of information) to diagnose and to prescribe treatment. While it is to be expected that the practitioner will trust the patient narration's about her symptoms, the doctor must also go through a "police investigation." This involves verifying the discourse of the patient through as many tools available to verify this narration and/or uncover what is behind it to detect relevant information for the diagnosis and treatment plan. The doctor also relies on visual clues to determine whether

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[215] *Ibid.*, p. 130
[216] *Ibid.*, p. 58
[217] *Ibid.*, p. 49
[218] Carel, H., Kidd, I.J., 2017. *Epistemic Injustice in Medicine and Healthcare*, in: *The Routledge Handbook of Epistemic Injustice, Routledge Handbooks in Philosophy*. Routledge, Taylor & Francis Group, London ; New York, p. 336.
[219] The gap between individual patient and experience and medical objectification is growing due to the increasing specialization of disease treatment. See: Weber, J.-C., 2017. *La consultation*, Presses Universitaires de France. ed., Paris. p. 56.

the patient before them is trustworthy.[220] Thus, the testimony of the person may not be considered reliable when either the examination or the physical signs of the patient contradict her testimony. What all this means is that for the person in front of them, doctors may not always consider the patient to be a reliable witness of their symptoms. In reference to epilepsy, for instance, the person giving testimony on the number of seizures they have had in the past month is often not reliable, as many patients lose consciousness during seizures. Thus the testimony of family members (or other members of the entourage) is often solicited by the doctor to complete the patient's testimony. This is not necessarily a case of testimonial injustice as the patient is an unreliable witness.

There are also the practical aspects of healthcare environments today to consider, which favor performance based results based on quantitative rather than qualitative views.[221] In these systems, patients' testimonies may be viewed as non-generalizable and discarded (as we have seen in the example of the patient's singing). All of these represent limits of the evidence-based model of medicine, but not necessarily a situation of epistemic injustice if patients have other ways of expressing their testimonies (such as in patient associations or with their families) or because they do not wish to share such testimonies with their doctors. As Carel and Kidd have pointed out, in the medical encounter, patients usually have limited capacities to contribute epistemically, by providing *factual information* relevant to the treatment plan rather than offering their *personal experience*.[222] A testimonial injustice may occur only if the patient desires to share this information and is prevented from doing so.

However, testimonial injustice becomes relevant when a person's testimony has been unjustly ignored due to *prejudice*. Empirical literature is full of examples of how the doctor exercises prejudices in medical care based on gender, minority group, and/or educational backgrounds, preventing the patient's speech from being treated with epistemic credibility. However, we may also consider that the social role of being a patient might be a criterion for prejudice. In other words, can a patient be seen as less credible in the doctor's eyes because of her illness? A practical example in the medical context of

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[220] This is an everyday practical habit, although of course it is not to be neglected that the doctor has more epistemic power to determine whether or not to take into consideration the speaker's testimony than the patient.

[221] Carel, H., Kidd, I.J., 2014. *Epistemic injustice in healthcare: a philosophical analysis*. Med Health Care and Philos 17, p. 535.

[222] Carel, H., Kidd, I.J., 2017. *Epistemic Injustice in Medicine and Healthcare*, in: *The Routledge Handbook of Epistemic Injustice*, Routledge Handbooks in Philosophy. Routledge, Taylor & Francis Group, London ; New York, p. 343.

testimonial injustice is when a question is posed by the patient to the doctor, and the doctor does not take the question seriously because it is coming from the patient. The testimony could also not be taken seriously because the doctor sees the patient as too "emotional."[223]

In addition, the process of the medical encounter itself could lead to epistemic injustice. As the medical encounter includes questioning, interrupting, stopping or filtering non-technical information from technical information, this can also result in an act of exclusion[224] or silencing of information that is relevant for the patient, but not necessarily for the doctor in the mission to diagnose or treat. In other words, in doctor's eyes, in this situation, the patient's testimony (because she is a patient) may receive a deflated level of credibility.[225]

These are some examples of when we can talk about testimonial injustice occurring in the healthcare context. However, there could also be also injustice due to the social infrastructure in place; for instance, doctors may want to practice Rita Charon's idea of *radical listening*,[226] but be unable to do so due to the time and resource constraints of their medical practice. Thus it may not be the healthcare provider's intent to practice testimonial injustice nor in her capacity to fully remedy it.[227] We can also understand that epistemic injustice may occur among healthcare professionals due to hospital hierarchies,[228] as some professionals are silenced or not given full epistemic credibility due to their relative status. However, the results of these formulations of epistemic injustice are particularly troubling for healthcare institutions, as they can cause patients to lose trust in healthcare providers and institutions, as well as lead to unnecessary medical tests or misdiagnosis.[229] It can also

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[223] Carel and Kidd maintain that ill persons are particularly vulnerable to testimonial injustice due to presumptive characteristics like cognitive unreliability and emotional instability. Carel, H., Kidd, I.J., 2014. *Epistemic injustice in healthcare: a philosophical analysis*. Med Health Care and Philos 17, p. 530.

[224] Waitzkin, H., 1989. *A Critical Theory of Medical Discourse: Ideology, Social Control, and the Processing of Social Context in Medical Encounters*. Journal of Health and Social Behavior 30, p. 231.

[225] In another article, Kidd and Carel discuss two forms of *epistemic complaints*, one coming from the patient who claims that healthcare professionals do not listen to their concerns, and one coming from physicians, who claim that patients provide them with irrelevant information. See: Kidd, I.J., Carel, H., 2017. *Epistemic Injustice and Illness*. J Appl Philos 34, p. 172–173.

[226] Charon first expressed this concept as "attentive listening" but the term "radical listening" has become more popular due to the radical listening project. For the idea of attentive listening, see Charon, R., 2005. *Narrative Medicine: Attention, Representation, Affiliation*. Narrative 13, 261–270. p. 262. For the radical listening project, see: Radical Listening: Healing Conversations – The Radical Listening Project [WWW Document], n.d. URL. https://wp.nyu.edu/radicallisteningproject/2018/03/16/radical-listening-healing-conversations/(accessed 5.14.19).

[227] Carel, H., Kidd, I.J., 2014. *Epistemic injustice in healthcare: a philosophical analysis*. Med Health Care and Philos 17, p. 535.

[228] Reed, P.G., Rishel, C.J., 2015. *Epistemic Injustice and Nurse Moral Distress*: Perspective for Policy Development. Nurs Sci Q 28, 241–244.

[229] Kidd, I.J., Carel, H., 2017. *Epistemic Injustice and Illness*. J Appl Philos 34, p. 173.

lead to further stigma of already stigmatized[230] illnesses.[231] This kind of epistemic injustice cannot only be rectified through training in communication skills or patient satisfaction questionnaires; it represents a more pernicious systemic problem that must be dealt with in order to change established medical practices.[232] However, epistemic injustice in healthcare is to be taken seriously, as it leads to patient and healthcare provider suffering, as well as increased healthcare costs.

Testimonial injustice and Patient Empowerment

In our discussion thus far on patient empowerment, we can see several ways in which patients suffer from testimonial injustice. In the first place, this thesis aims to move toward a patient-developed model because it is currently absent. If we take into account patient empowerment discussions based on the biomedical model, the patient has been wronged in the sense that 1) their view has not been solicited in the development of the empowerment model; 2) they have been spoken *for* by healthcare providers, economists, and policy makers. We maintain that this is a matter of epistemic injustice because prejudice has occurred somewhere in these formulations, which has prevented these views from being heard. This prejudice may stem from their status as patients or their lack of epistemic privilege in healthcare institutions, but also because their singular qualitative expressions of illness experience do not harmonize with the quantitative view.

However, despite this strong assertion, we are not saying that this act of testimonial injustice is either deliberate or an act of bad faith. Fricker emphasizes that epistemic injustice can happen whether or not the person believes that this injustice acceptable. The reason we may perpetuate testimonial injustice despite our beliefs[233] is partly the result of historical circumstances as well as our social practices. For instance, as we have discussed, many healthcare providers believe in the value of having the patient participate; however, they may still perpetuate these entrenched social prejudices in daily practice through a variety of unintentional heuristics.

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[230] For an example of how stigma is perpetuated through epistemic injustice, see: Sanati, A., Kyratsous, M., 2015. *Epistemic injustice in assessment of delusions: Epistemic injustice in delusions*. J Eval Clin Pract 21, 479–485.

[231] For an example of how epistemic injustice can lead to specific problems in psychiatry, see: Scrutton, A.P., 2017. *Epistemic Injustice and Mental Illness*, in: *The Routledge Handbook of Epistemic Injustice, Routledge Handbooks in Philosophy*. Routledge, Taylor & Francis Group, London ; New York, pp. 347–355.

[232] Kidd, I.J., Carel, H., 2017. *Epistemic Injustice and Illness*. J Appl Philos 34, p. 174.

[233] This is what Fricker calls "residual internalization." Fricker, M., 2009. *Epistemic injustice: power and the ethics of knowing*, 1. publ. in paperback. ed. Oxford University Press, Oxford. p. 36-37.

In addition, we have to take into consideration the historical scars of medical paternalism. It remains challenging — in the way that medicine is practiced, taught, and conceived today — to give full epistemic justice to patients in the medical encounter. For these reasons, we can see that testimonial injustices will persist even when we speak of the expert patient or the empowered patient today. However, that is not an excuse to leave the situation as it is. For her part, Fricker suggests some practical tools to help us to rectify testimonial injustice, notably through critical self-awareness[234] (a concept quite similar to ideas used in the empowerment movement). The ultimate end of this type of correction is both *justice* (from the ethical perspective) and *truth* (from the epistemic view) to the person wronged in her capacity as a knower. One of the ways to develop this critical self-awareness is to listen to and solicit the patient's perspective. The methods outlined in this thesis contribute to the development of this critical sensitivity for healthcare institutions today.

1.7.2. Hermeneutical Injustice

Hermeneutical injustice has also been applied to the healthcare context in recent literature.[235] Fricker says this is characterized by, *"the injustice of having some significant area of one's social experience obscured from collective understanding owing to hermeneutical marginalization."*[236] For it to be hermeneutical injustice, there must be 1) the existence of hermeneutical marginalization that 2) disables the person to communicate a significant realm of social experience in a way and 3) that systemically disadvantages these marginalized groups.[237]

Fricker argues that socially excluded groups suffer from a rupture between understanding and their experience. This makes it difficult to convey their experience to others, to make sense of it, but also to be accepted as trustworthy in the encounter. Thus testimonial injustice and hermeneutical injustice often intertwine. In this type of injustice, exclusion is based upon the prejudice in the collective knowledge resource, thus there is no "listener" but rather a discriminatory structure which is the source of the injustice.

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[234] *Ibid.*, p. 91
[235] Notably in Carel, H., Kidd, I.J., 2014. *Epistemic injustice in healthcare: a philosophical analysis*. Med Health Care and Philos 17, 529–540.
[236] Fricker, M., 2009. *Epistemic injustice: power and the ethics of knowing*, 1. publ. in paperback. ed. Oxford University Press, Oxford. p. 158.
[237] Wardrope, A., 2015. *Medicalization and epistemic injustice*. Med Health Care and Philos 18, p. 344.

Essentially it means that because of the environment, it is hard for the speaker to convey what she is trying to say and to make it understood by others.

The first idea of hermeneutical injustice in the healthcare realm relates to medicalization, in the recurring idea that medicine's epistemic authority crosses out all our understandings of illness.[238] There is little doubt that medicine's hermeneutical privilege has been established by society's validation of medicine's authority/expertise. However, in light of our previous discussion, we can also add that it has also been validated by the patient, who seeks this expertise. Thus the fact that the healthcare provider has a certain epistemic privilege is not necessarily an injustice; indeed it has certain benefits to society. In the first place, this expertise has developed for the use of society, to help patients to treat or cure their diseases. In addition, medicalization can also to illuminate our understandings of our illness experience (although it may also cancel out patients' experiences, as discussed).[239] Thus we do not maintain that this epistemic privilege is bad and it may even be necessary to allow healthcare providers to be effective in their jobs.

This type of injustice, however, occurs when through epistemic privilege, the healthcare system or medical experts come to dominate and push out other discourses. An example of this is the chronic fatigue syndrome; as the medical community does not have the vocabulary to diagnosis or treat the syndrome, patient experiences have been sidelined.[240] In this case, both testimonial and hermeneutical epistemic injustice have occurred: in consultations, patient testimony is ignored or discredited (testimonial injustice), but patients themselves are also not able to make sense of their experiences because it does not fall under dominant medical discourses and understandings (hermeneutical injustice).[241]

However, overall we are cautious to label medicalization as hermeneutical injustice. For Wardrope, this very act of labeling can even lead to epistemic injustice. He argues that in dominant critiques of medicalization, we assume patients are simply "dupes" or "prisoners" of medicalization,[242] thus encouraging discretization of patient's views when they highlight the positive aspects of medicalization.[243] In other words, let us not assume

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[238] *Ibid.*, p. 344.
[239] *Ibid.*, p. 346.
[240] Blease, C., Carel, H., Geraghty, K., 2017. *Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome*. J Med Ethics 43, p. 549.
[241] *Ibid.*, p. 551-552.
[242] Wardrope, A., 2015. *Medicalization and epistemic injustice*. Med Health Care and Philos 18, p. 350.
[243] *Ibid.*, p. 349.

that patients are stupid: they openly question medicalization and its limits, and therefore are not necessarily its victims (just as we have said, let us not assume that patients are necessarily unempowered!). However, when this injustice occurs, there are remedial strategies. As a corrective measure for hermeneutical injustice, Wardrope argues for epistemic humility[244] to capture awareness of one's own epistemic limitations, as well as encouraging alternative information seeking.

Carel and Kidd, the two theorists who have most thoroughly contextualized epistemic injustice for the healthcare context, also argue for hermeneutical injustice due to the gap for patients in collective hermeneutical resources to describe their experience of illness.[245] While cases such as chronic fatigue syndrome make a good case for this type of injustice, we cannot fully agree with their assertion. In the first place, it seems impossible at times to describe what happens in one's body; we may lack collective hermeneutical resources to do so, but perhaps this is simply because these experiences are to a certain extent indescribable. Carel and Kidd go on to say that this is perhaps because these experiences cannot be explained in any direct, propositional manner and thus patients only share these experiences with those who can understand (such as other patients). However, even if this is the case, has hermeneutical injustice occurred? Viewing the ability to relate illness experience through only the lens of the doctor-patient relationship presumes that this is the proper place for this type of discourse. We are again talking *for* patients instead of *with* them. Injustice occurs when the patient wishes to discuss these views with the doctor and their experiences are ignored. Here we are again talking about testimonial injustice, not hermeneutical injustice.

However, we do agree that hermeneutical injustice may be occurring for patients in patient empowerment terms. Based on our research, patients do not know what to make of patient empowerment: many do not understand its meaning and cannot understand how it relates to their experiences. It is for this reason that we have solicited a patient-developed definition of patient empowerment as the ambition of this thesis. In other words, if the biomedical model of patient empowerment has no meaning for patients, we may be speaking of hermeneutical injustice as patients themselves are not able to attribute or

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[244] Wardope defines epistemic humility as, *"a critical self-awareness of one's own epistemic limitations together with a disposition to seek out complementary and contrasting perspectives that may assist in overcoming these limitations; and a resolution to promote publicly both the awareness of those limitations, and the alternative authorities that aid in overcoming them." Ibid.*, p. 351.

[245] Notably in Carel, H., Kidd, I.J., 2014. *Epistemic injustice in healthcare: a philosophical analysis*. Med Health Care and Philos 17, p. 529.

understand their illness experiences in light of these conceptions. Another point which we concur with Carel and Kidd is that, despite attempts to take into account patient experience with patient-centered or other recent initiatives, individual understandings have largely been discarded in clinical services, clinical evaluations, or in clinical guidelines, as the qualitative nature of such accounts make them difficult to feed into quantitative evaluations.[246] Thus there is a problem both with understandings by patients themselves as well as their capacities for epistemic input into programming designed for them. We therefore maintain that both types of injustice are present in patient empowerment discussions and both feed into the problem.

[246] Carel, H., Kidd, I.J., 2017. *Epistemic Injustice in Medicine and Healthcare*, in: *The Routledge Handbook of Epistemic Injustice*, Routledge Handbooks in Philosophy. Routledge, Taylor & Francis Group, London ; New York, p. 341.

1.8. Other Conceptions of Patient Empowerment

The final section of this chapter will define and analyze other models of patient participation, in particular patient activation, patient engagement, and patient partnership. As we have already discussed, we have chosen to use the formulation of patient empowerment over these other conceptions. While we highlight the difficulties of these three approaches by way of illustration, each concept also has a number of advantages which will be elaborated and will help us move forward with the approach we are seeking to defend. Before moving to these concepts, however, it will be necessary to demarcate the differences between patient empowerment and patient/person-centered care.

1.8.1. Patient-Centered Care

An extensive body of literature has emerged in the last fifty years advocating for the so-called patient-centered care (PCC) approach. While the PCC approach shares some common goals with the patient empowerment approach, there are also some important differences that will need to be highlighted. Like empowerment, patient-centered care is often advocated for based upon ethical claims, as it is seen as a means to move beyond paternalistic approaches to enable a care plan centered on the patient. It stems from the same ideas surrounding society's call of the patient's right to participate and like patient empowerment, it remains more an ideal theory than a reality today.

Like the terms autonomy and patient empowerment, patient-centered care (or its other formulations such as "person-centered care"[247], "client-centered care," "user-centered care" etc.) suffers from a lack of conceptual precision owing to the diversity of ideas and

[247] Ekman et al., argue that person-centered care is a step forward beyond patient centered care. They notably say that the word "patient" tends to reduce the person to a passive role as the recipient of medical services, while using the words "person-centered care" will help transform medical practice by highlighting practices which encourage knowing a person as a human being, encouraging the person to be active in their healthcare plan, and for factors such as emotions and feelings to be taken into account. We agree with this wording, which accords with the ideas shown in this project of patient life empowerment. However, in this section, we use the word "patient centered care" to place emphasis on the differences in the origin of the concept (coming from the medical sphere) vs. patient empowerment (supposedly coming from the patient). For a discussion on this subject, as well as differences between PCC and personalized medicine, see: Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I.-L., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L.-E., Rosén, H., Rydmark, M., Sunnerhagen, K.S., 2011. *Person-Centered Care — Ready for Prime Time*. European Journal of Cardiovascular Nursing 10, p. 249.

ways that the notion has developed in healthcare institutions. We will not provide an extensive analysis or history of the idea, but we will highlight interesting aspects of it for our purposes. The original term can be traced to 1969, when Balint introduced the idea of patient-centered medicine as a new methodology for medicine.[248] According to him, patient-centered medicine has a double aim. He says that, *"in addition to trying to discover a localizable illness or illnesses, the doctor also has to examine the whole person in order to form what we call an 'overall diagnosis.' This should include everything that the doctor knows and understands about his patient; the patient…has to be understood as a unique human-being."*[249] We have already seen some of the problems of operationalizing this method through Balint's case study in our previous discussion. However, in newer formulations of the PCC perspective, there is also an emphasis on a larger participation for the patient, not only in providing information for the healthcare provider, but also by participating in healthcare decision-making in the form of patient empowerment or another model of patient participation.

Today's advocacy for PCC is largely based upon the biomedical model that we have described for patient empowerment, with some additional outcomes envisaged. Possible outcomes of the patient-centered approach are thought to include patient adherence and knowledge, but also greater efficiency, a decrease in healthcare costs, improved healthcare quality, and patient satisfaction.[250] Although largely based upon the biomedical model we have described, the approach also has eye not only to increasing patient's capacities but also openly contributing to healthcare institutions' "efficiency" and "effectiveness" (unlike patient empowerment, where these claims are often present but hidden). As we can immediately see from the discussions preceding this section, prioritizing patient's participation and at the same time healthcare institutions' desire to be more efficient and effective will likely face conflicts on the ground.

Let us further investigate the various conceptual approaches of PCC in order to understand its main differences from patient empowerment. Robinson *et al*. identifies four conceptual approaches used for the advocacy of the PCC approach: the public policy perspective, the economic perspective, the clinical perspective, and the patient

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[248] Balint, E. 1969. *The Possibilities of Patient-Centered Medicine.* The Journal of the Royal College of General Practitioners 17 (82): 269–76. p. 269.
[249] *Ibid.*
[250] Castro, Eva Marie, Tine Van Regenmortel, Kris Vanhaecht, Walter Sermeus, and Ann Van Hecke. 2016. *Patient Empowerment, Patient Participation and Patient-Centeredness in Hospital Care: A Concept Analysis Based on a Literature Review.* Patient Education and Counseling 99 (12). p. 1930.

perspective.[251] These four definitions are centered on the relationship (between the healthcare provider and the patient) as well as the "result" of the relationship (the care plan). The following are the four definitions cited by the researchers:

Table 1: Patient-Centered Care Definitions

1. **Public policy definitions**
Doctor-patient relationship: focus on patient partnership, participation, education *Care:* organized to reflect respect for patients' needs and values
2. Economic definitions
Doctor-patient relationship: shared decision-making and empowerment *Care:* "supply and demand" care model based on patient demands for cost/quality/convenience
3. Clinical practice definitions
Doctor-patient relationship: recognizing the patient as a person, focus on self-care/the family *Care:* focused on tailoring the treatment plan to the individual patient, including by taking into account biopsychosocial factors
4. Patient definitions *have not been developed*. The researchers use patient preferences for this definition.
Doctor-patient relationship: focus on patient partnership and involvement *Care*: organized to show respect for the patient through communication, giving adequate time, thinking of the patient as a priority and treating the patient with respect.[252]

From these categories, we can highlight a number of features of patient-centered care. The first is the focus on the doctor-patient relationship. As patient-centered care is related to healthcare, it is formulated as a relationship with formal healthcare institutions through the doctor-patient relationship. While PCC and patient empowerment both see a changing way of thinking about the doctor-patient relationship, they come from different foundations. As discussed at the beginning of this chapter, the idea of empowerment came from political and social movements; PCC, however, was largely conceived and built for

[251] Robinson, Janice H., Lynn C. Callister, Judith A. Berry, and Karen A. Dearing. 2008. *Patient-Centered Care and Adherence: Definitions and Applications to Improve Outcomes.* Journal of the American Academy of Nurse Practitioners 20 (12). P. 601-602.
[252] These categories are Robinson *et al.*'s categories but some wording has been changed for brevity/clarity. *Ibid.*

healthcare. According to Castro *et al.*[253]., this means that patient empowerment can go beyond the medical context, while PCC is largely regulated to the medical domain. In other words, PCC can stimulate an "empowering healthcare relationship" for the patient/healthcare provider while patient empowerment both includes and goes beyond the healthcare relationship.[254]

Secondly, these definitions advocate for a greater involvement of the patient into the treatment plan (which becomes personalized). In this conception, the patient-centered approach stems from the logic we are already familiar with under Biomedical Claim 3 (a greater participation for the patient and the healthcare provider, leading to a greater partnership and a personalized treatment plan). We have already discussed the difficulties of achieving this for patient empowerment.

A third idea that appears in PCC is the idea of seeing the patient not just as a patient, but also as a person with goals and priorities not directly related to healthcare. The ways to do so vary: by taking into account biopsychosocial factors, by treating the patient with priority and with respect, or by organizing individual care according to the patients' needs and values, by encouraging narratives in the clinical encounter, etc.[255] Treating the patient as a person is not a highlighted feature of patient empowerment, probably because it is obvious in patient empowerment formulations that a patient is a person, as that person will want to and is expected to act (*the patient gaining power to act through empowerment*). Therefore, this idea is not in conflict with patient empowerment approaches and may even provide the vision we need to have the patient be empowered to act in the healthcare relationship. We maintain therefore that PCC is complementary to the idea of patient empowerment: an empowered patient may help achieve the aims of PCC, although the idea of PCC is not sufficient to encompass the idea of patient empowerment.

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[253] Castro, Eva Marie, Tine Van Regenmortel, Kris Vanhaecht, Walter Sermeus, and Ann Van Hecke. 2016. *Patient Empowerment, Patient Participation and Patient-Centeredness in Hospital Care: A Concept Analysis Based on a Literature Review.* Patient Education and Counseling 99 (12). p. 1930.

[254] *Ibid.*

[255] A model currently to achieve person-centered care in practice in the European Union has arisen through the so-called Gothenburg group at the Gothenburg Centre for Person-Centred Care (Sweden). This model combines three routines: 1) Initiating a partnership through patient narratives; 2) Shared decision making from professionals, patients, and families to work together toward commonly agreed goals; and 3) Safeguarding the partnership through documentation of patient preferences, values, and patient involvement in care. The group is at the time of writing leading a European Union project to coordinate this idea throughout Europe and is providing trainings for healthcare providers. For more information, see: Britten, N., Moore, L., Lydahl, D., Naldemirci, O., Elam, M., Wolf, A., 2017. *Elaboration of the Gothenburg model of person-centred care.* Health Expect 20, p. 408.

However, one of the strengths of PCC definitions for our purposes is the focus on the idea of what is a good outcome: according to the public policy definition of PCC, a good outcome is the personalized treatment plan that takes into account (or harmonizes with) patients' needs and values. Therefore, it partly solves the problem that we have posed in this chapter: whose needs and values should we prioritize in terms of outcomes, the doctor's or the patient's? The PCC model answers this for us (the answer is the patient's).

Another strength of the PCC approach for our discussion is in seeing "the patient as a person" in the healthcare relationship. Patients in the PCC model are not necessarily viewed as "disempowered and in need of empowerment" but rather unique individuals with individual biographies, preferences, needs and values. It is easier in this conception to understand how we can see patients as active partners compared to a disempowered patient in need of empowerment. In addition, even if the patient does not wish to participate in the sense of fully shared decision-making, the patient's needs and values will be taken into account. Therefore, it partly solves our problem of whether the patient can and will participate: patients will participate as they are *capable* of doing.

However, there are some problems with merging the PCC approach with patient empowerment. In the first place, according to the definitions we have highlighted, the term patient empowerment is highlighted in the economic model, which sees patient participation in terms of fully shared decision-making and making choices based upon factors such as cost, quality, and convenience. This model assumes that the empowered patient is a full actor, taking into account individual and society's needs in their healthcare choices. The economic model even sees patients as consumers, envisaging a role for them in balancing demand and supply. This may give "power" to the patient, and in this conception the empowered patient is indeed the patient that has the "power" to choose between healthcare providers and other solutions. However, it also imposes obligations for patients to make choices that are "good for society." In the economic models, patients are empowered more out of duty than out of choice.

Another difficulty is that the other (non-economic) approaches see the patient working actively with the healthcare provider, but not outside of it. In this perspective, we have both not moved beyond the patient-doctor relationship in patient empowerment terms nor have we witnessed a clear participation for the patient beyond the biomedical claims that we have already discussed. As we advocate seeing patient empowerment both as an individual person's action (in the doctor-patient relationship), but also as a person in society, this implies that patient empowerment may be beyond healthcare.

A further troubling aspect is the lack of patient-developed definitions. This means that the impetus for PCC has come from healthcare institutions and not from patients themselves. As such we are led to wonder if the PCC concept has resonance for patients themselves. For further research, it would be interesting to develop a patient-developed definition of patient centered care in order to move it forward from the patient's point of view and to understand whether it corresponds or conflicts with the patient's perspective.

1.8.2. Empowerment Caring

The second idea we will explore is empowerment caring. McKay, Forbes and Bourner propose the idea of *empowerment caring* as a situation in which, "*the doctor and the patient are mutually active, they respect one another's needs and they work together to achieve a result.*"[256] This formulation of empowerment does not describe a power relationship, such as the transfer of power from the doctor to patient, but rather one of mutual help and sharing. This type of empowerment largely corresponds to the third claim of the biomedical model: that when the doctor and patient work together, they will be able to achieve a more personalized treatment plan acceptable to both actors.

What is different from the biomedical claim is the idea of needs, and the assumption that both the patient and the doctor will "respect each other's needs." While the authors do not define what they mean by needs, their formulation suggests that 1) each person in the relationship has concrete needs; 2) these needs are somehow necessary to achieve a result.[257]

What is interesting for our discussion is the idea that both needs (that of the doctor and that of the patient) are valuable and should be taken into account. From the patient's side, we can imagine that these needs might include to participate as is possible and desirable; to have a healthcare plan in line with their values; and in general the need to be seen as a person and not (just) as a patient. Under this formulation, we will also have to look at the doctor's needs. We can imagine this might mean the need to have their expertise recognized; the need to respect the doctor's role; the need to recognize the time

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[256] McKay, B., J. A. Forbes, and K. Bourner. 1990. *Empowerment in General Practice. The Trilogies of Caring*. Australian Family Physician 19 (4): 513, 516–20.

[257] This formulation is similar to Nordenfelt's definition of needs as "the necessary conditions for the realization of a goal." Nordenfelt, L., 1995. *On the nature of health: an action-theoretic approach*, 2, rev. and enl. ed., Philosophy and medicine. Kluwer, Dordrecht. p. 59

and resource constraints in which doctors do their jobs; but also the need to be seen as persons and not (just) as professionals.

However, these needs are somehow tied to the realization of a goal: a healthcare plan acceptable to both. Here we see the same difficulties as in the biomedical model (Claim 2). In particular, how do we integrate both the doctor's and the patient's needs into the healthcare relationship to enable a healthcare plan acceptable to both parties? While *empowerment caring* implicates that both needs — that of the doctor and that of the patient — should be valued from an ethical standpoint, on the ground, we will run into difficulties by not choosing one side over the other as we cannot guarantee that they will have the same, or even compatible, needs. We will need to decide in these formulations of empowerment who should take precedence, the doctor's needs or the patient's needs, even while recognizing and doing our best to ensure that both needs are met.

We can see this challenge by returning to refractory epilepsy. A part of the doctor's need — due to institutional responsibilities and time constraints — will to be able to see a certain number of patients per day within a certain schedule. The doctor will also need time to rest, time to do research, or time to consult with colleagues. This will necessarily limit the time dedicated to each patient. However, refractory epilepsy patients may have a variety of complex needs—the need to discuss their treatment, but also social and psychological difficulties that may influence their treatment and their ability to live well with their disease. Patients may need to discuss these issues with their physician to enable a better treatment plan, to find a sympathetic ear, or even to understand what they can and cannot do in their life due to their disease. While some of these tasks could be handed over to other professionals, patients have immediate needs, or may feel more comfortable asking this particular provider to fulfill these needs rather than others. We certainly hope that the doctor is able to dedicate sufficient time to the encounter to take into account of all these needs. However, this is not always realistic, both due to the healthcare infrastructure in place, but also the doctor's needs from the perspective of himself as a person and his corresponding availability for each patient. Therefore, the patient's needs and the doctor's need will not (always) and certainly not necessarily correspond. To use O'Neill's formulation for informed consent[258], we therefore cannot guarantee and therefore not require that both of their needs will be taken into account. If the healthcare infrastructure

[258] O'Neill, Onora. 2002. *Autonomy and Trust in Bioethics*. Gifford Lectures 2001. Cambridge ; New York: Cambridge University Press. p. 37

does not permit these needs to correspond, we could suggest that we will need to modify this infrastructure to move toward *empowerment caring*; however, even by doing so, the differing needs of the doctor and of the patient as "persons" will still not necessarily correspond.

Therefore, as an ideal, and an ideal to work toward, *empowerment caring* is admirable, as it allows us to understand patient empowerment as a relationship, in which both sides have needs. In addition, its focus on needs suggests that we need to pay more attention to a more systematic, global idea of needs rather than just the patient's right to be informed. However, at some point, on the ground, a choice will need to be made. We maintain that at the end of the day, the patient's needs should take precedence, given that the treatment ultimately affects them. That is not to say that we should ignore the doctor: in order to be available to support the patient, a certain number of the doctor's needs will need to be met; however for our purposes (and because it has not been sufficiently solicited), we will focus in this thesis on the patient.

1.8.3. Patient Activation

The term "patient activation" has been popularized by a tool developed to measure it, the so-called Patient Activation Measure® (PAM®) which its developers define as, *"an individual's knowledge, skill, and confidence for managing their health and healthcare."*[259] Developed by Dr. Judith Hibbard at the University of Oregon, it is licensed by Insignia Health.[260] Since its introduction, more than 450 academic articles published on the subject.[261] It is widely used in the United States and in the United Kingdom (but has also been translated in many languages and contexts). PAM® defends the idea that activated patients who believe that they have important roles to play in collaboration with the healthcare provider will learn how to manage their disease to promote better health behaviors. It therefore stems from Biomedical Claim 1, but also encourages Biomedical Claim 4, through "better health behaviors." PAM® has defined four stages of activation:

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[259] Hibbard, Judith, and Helen Gilburt. n.d. *Supporting People to Manage Their Health: An Introduction to Patient Activation*, p. 54.
[260] "Insignia Health." n.d. Accessed March 13, 2019. https://www.insigniahealth.com/company/about-us.
[261] *Ibid.*

- *Firstly, belief that the patient role is important*
- *Secondly, the confidence and knowledge necessary to take action, including knowledge of medications and lifestyle changes, confidence in talking to healthcare providers and knowing when to seek help, and (at slightly higher levels of activation) confidence in following through on recommendations, knowing the nature and causes of the health condition, and different medical treatment options.*
- *The third stage involves actually taking action, including maintaining lifestyle changes, knowing how to prevent further problems, and handling symptoms on one's own.*
- *The fourth stage involves actually staying the course even when under stress. Patients who endorse these items are confident they can maintain lifestyle changes when under stress, that they can handle problems (rather than simply symptoms) on their own at home, and that they can keep their health problems from interfering with their life.*[262]

A person's level of activation in these stages is assessed via a questionnaire that was designed with input from experts in the treatment of chronic disease.[263] The PAM® questionnaire includes questions about the patient's knowledge of medication, the causes of their condition(s), and the ability to problem-solve, among others. The measure is not specific to an individual disease (although it has now been used to research specific diseases[264]). Additionally, it does not ask whether the person actually engages in the self-management behaviors described in the questionnaire (but to be fair to the PAM®, this would be hard to measure via a questionnaire and might lead to misleading results).

The measure has so far been used on the ground in three ways:[265] first, it helps clinicians anticipate what type of discussion the patient may benefit from before an appointment begins. From the point of view of the PAM®, it is not necessary to make a linear progression through the various stages of patient activation; however, it does guide clinicians to assess the patient's progress. Secondly, the activation scores are used for electronic records, thus providing a record monitoring activation. Thirdly, PAM® is being

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[262] Hibbard, J.H., Stockard, J., Mahoney, E.R., Tusler, M., 2004. *Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers*. Health Services Research 39, p. 1005-1016.

[263] Hibbard, J.H., Mahoney, E.R., Stockard, J., Tusler, M., 2005. *Development and Testing of a Short Form of the Patient Activation Measure*. Health Serv Res 40, p. 1918.

[264] See for instance: Stepleman, Lara, Marie-Christine Rutter, Judith Hibbard, Lisa Johns, Dustin Wright, and Mary Hughes. 2010. *Validation of the Patient Activation Measure in a Multiple Sclerosis Clinic Sample and Implications for Care.* Disability and Rehabilitation 32 (19): 1558–67.

[265] Gibert, Sophia H, David DeGrazia, and Marion Danis. 2017. *Ethics of Patient Activation: Exploring Its Relation to Personal Responsibility, Autonomy and Health Disparities.* Journal of Medical Ethics 43 (10): 670–75. p. 672.

used as a guide for research and evaluation of healthcare providers and organizations, as it provides a means to measure whether increased scores over time can serve as a patient-centered outcome measure and indicate quality improvement.[266] PAM® is thus a powerful — and easy to use — quantitative tool that can be used by healthcare teams and institutions to monitor a patient's progress in activation/empowerment. Organizations that use PAM® today do so primarily based on Biomedical Claim 4, the assumption that patients with high PAM® scores will have better health outcomes.

Having introduced the tool, let us now discuss its use in healthcare institutions. First of all, the way in which the patient's role is formulated puts the patient at the center of the activity but not as an actor: we speak of the activation of the patient in an indirect way, not of the patient as a subject (the patient who acts). This definition makes the patient a process being realized or accomplished (activation) rather than the subject who is acting. In steps three and four of the measure, we do see a patient that is acting (taking action to maintain lifestyle changes even under stressful situations, and staying the course in time). However, the patient is evaluated as acting only according to the criteria defined by the measure (and even then, it measures confidence to stay the course, rather than real action).

Why would the architects of PAM®, who seem to want to take a departure from the term empowerment, prefer this formulation rather than the translation closest to French, such as patient actor? Was it to avoid the double meaning that the patient is pretending (he's acting like an activated patient, therefore "he's acting") or is it put the emphasis on the process of activation that is quantifiable (a step to reach)? The word choice of patient activation suggests that the principal interest of the PAM® is to give a way for the healthcare provider to measure patient behavior (and is used this way in practice). If the patient fills in the questionnaire, it is not her that decides what it means to be activated; thus it remains a tool developed for the healthcare provider to assess the patient. It also does not respond to the question of why the patient should follow these various stages of activation.

Furthermore, the tool does not show us the patient's knowledge that can be mobilized in each step of the relationship with healthcare providers (2) but also in their outside life (1+3+4). The measure also does not solve the problem already highlighted: whether the patient will actually act upon this knowledge gained. Finally, the measure does not take into consideration the role of others not inherent to this two-way relationship

[266] *Ibid*. p. 671.

(family, patient association, society), in each step of the process. Its main benefit from our perspective is that it provides a holistic view of the patient beyond the clinical encounter.

However, there are several worrying aspects to the tool when used on the ground. We are not suggesting that the measure itself is responsible, but rather that a narrow interpretation might have worrying implications both for the doctor-patient relationship and for patients. Gibert *et al*.[267] have highlighted several of these concerns: the first is that activation may be asking patients to believe they may be (morally) responsible for their health behaviors. We cannot clarify with this measure — or any others — if failing to participate actively in one's healthcare is or is not morally wrong. We have argued elsewhere that it is the patient's right to decide when and how to be empowered and we do not wish to advocate its imposition. However, this tool does give doctors a means to measure and blame patients who do not "rise up" on the scale of patient activation. It could result in stigma and even worse, denial of healthcare to those who do not measure up to this scale. However, it could also lead to unrealistic expectations by the patient. Although health behaviors may be a vital part of managing chronic disease, patients will (usually) not be cured by their health-related behaviors, even at the highest level of activation.[268] Thus PAM could provide a means of increasing health-related behaviors with an end goal of better results (from the biomedical point of view), while the treatment itself proposed might not make this happen (leading to patient dissatisfaction).

Another problem comes to the forefront in terms of imposing certain behaviors. PAM® asks patients to develop not only their capacities to act but also to use them. They do this notably under criteria 3, which involves patients, "*taking action, including maintaining lifestyle changes, knowing how to prevent further problems, and handling symptoms on one's own.*" Even if the measure does not actually assess whether the patient actually engages in successful self-management behaviors, nor defines what these behaviors specifically could be, its emphasis is translating the idea of being activated into a series of actions. Patient activation under this conception goes head to head with the patient's right to choose whether to act and how to do so. Even if these actions are not punished in a careful reading of PAM®, they still imply a course to follow, dictated to a certain extent from a medical authority. As the PAM® has been advocated as a better way

[267] *Ibid.* p. 671-674.
[268] *Ibid.* p. 673.

to enhance patient autonomy in a way that compliance-based strategies do not,[269] we must now wonder whether PAM® does so if it is advocating certain actions. In other words, we return once again to the problem of what actions patients have the freedom to act upon.

Despite these problems, an interesting idea to come out of PAM® is its temporal (and non-linear) vision. Having the knowledge, capacity, and confidence to manage health and healthcare shows us a long-term activity that needs to be mobilized on a continual basis. With the word *activation*, we are looking for solutions so that patients put into place their knowledge and behaviors in time (3 + 4) even in stressful situations, not only to acquire this knowledge once and for all (1 + 2) as a definitive outcome. Patient activation is thus an interesting way to understand patient empowerment in a temporality. It is not only important for patients to understand and to manage their healthcare (a punctual activity put into place by programs like therapeutic education), but also the desire to put into this knowledge in daily life (thus the desire to act today but also tomorrow and after tomorrow). This shows us that patient activation (or empowerment) is dynamic: patients will change in their lifetime, and their strategies to live with their diseases will change with them.

1.8.4. Patient Engagement

Patient engagement is the third term that we will explore. According to Higgins *et al*.[270], the term "patient engagement" has increased markedly in scientific literature since its introduction in the 1990s, even if it remains less well known than its partner terms, patient empowerment and patient activation. The United States National Coordination of Health Information Technology even described patient engagement as a "blockbuster drug," one of the most underutilized resources in healthcare.[271] Why this interest in engagement vs activation or empowerment? What does it mean to be engaged in healthcare?

Development of this idea is very close to patient or person-centered care. If patient activation and patient empowerment are often seen as individual behaviors helped by

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[269] *Ibid*. p. 671.
[270] Higgins, Tracy, Elaine Larson, and Rebecca Schnall. 2017. *Unraveling the Meaning of Patient Engagement: A Concept Analysis.* Patient Education and Counseling 100 (1). p. 30.
[271] Dentzer, Susan. 2013. *Rx For The 'Blockbuster Drug' Of Patient Engagement.* Health Affairs 32 (2): 202–202. p. 202.

healthcare institutions but accomplished by the "autonomous" patient (even if we've seen the problems of putting these two together), what is interesting about patient engagement is that it is describing a behavior that is taking place in a relationship. After all, we cannot "engage" alone, we need someone to engage *with*. In addition, the term empowerment or activation can be seen as the antecedent or the result of a process of engagement, therefore these processes are complementary or cross each other[272] as patient engagement can come before or after these two terms and can even be the cause of activation or empowerment.

However, the term patient engagement like patient empowerment causes confusion, notably because it is mixed with ideas of empowerment or activation. Higgins *et al*. have consolidated the different definitions of patient empowerment in academic literature to see what distinguishes this term from patient empowerment and patient activation. Their definition helps us to understand these differences. For them, patient engagement is: "*the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual in cooperation with the healthcare provider or institution in the interests of maximizing outcomes or experiences of care.*"[273]

This definition has three parts: the desire and capability to participate; the choice to personalize this activity in relationship with the healthcare provider; and the idea of going toward a result. Desire and capacity to participate in healthcare decisions do not distinguish the term from activation; however, how the activity will happen is detailed (in cooperation with the healthcare provider). They call this the "therapeutic alliance" (i.e. allying with healthcare providers and institutions).[274] Patient engagement maintains the essential connection of the patient and the healthcare provider and tells us that the patient does not act alone but in a relationship. It therefore shows us the relational space to understand the patient in cooperation with the healthcare institution, which is not necessarily, or not only, based upon a financial transaction. It therefore keeps the aspect of hospitality important to healthcare unlike other possible definitions.

Another strong point of this definition is the possibility to see the activity (in which the persons are engaged) as personalized: *"to actively choose…in a way uniquely appropriate to the individual."* Recognition that each patient is different and will react differently to his disease help us go toward something that is more patient-centered, even

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[272] Higgins, Tracy, Elaine Larson, and Rebecca Schnall. 2017. *Unraveling the Meaning of Patient Engagement: A Concept Analysis.* Patient Education and Counseling 100 (1): 30–36. p. 31.
[273] *Ibid.*, p.31
[274] *Ibid.*, p.32

personalized, especially because it is with desire and with capacity that the patient acts. With engagement, we are a step closer to the idea of the patient as a subject of healthcare and not just as a quantifiable tool. We also have the vision of patients engaged according to their capabilities and desires.

However, we must now raise several objections. What remains unsatisfying just as in other definitions of patient empowerment or in patient activation is the desire for the patient to, *"maximize the result or the experience of healthcare"* which is coordinated with Biomedical Claim 4. As we have shown in PCC models, we do not know if maximizing the result is the result for the healthcare provider or the result for the patient. In addition, the word "engagement" is problematic in reference to the biomedical claims we have discussed in this chapter. As Pierron[275] shows, our conception of contemporary engagement is less collective and more individual. This means that we only act if we feel like acting, and that supposes the liberty to also disengage.[276] If patients are acting according to their desire and according to their capability, this does not imply that they are acting either for their well-being or for the well-being of society, nor that they will continue to engage in a durable time frame. The muddy wording of patient engagement therefore puts into focus the main problem we have highlighted in this chapter: what are we talking about here, the patient's right to engage (or to be empowered?) or the patient's responsibilities to do so?

The strength of the idea of patient engagement for our purposes is that it helps us see the patient as a real actor, in a relationship (not in full autonomy, but in relationship with the healthcare provider). It moves us closer to the realities of healthcare; however, while we salute the possibility for the patient to "disengage," or to become "less active" in certain temporalities of the doctor-patient relationship, in this thesis, we are not seeking only engagement but also increased capacities to act in ways appropriate to the patient. Therefore, the idea of patient engagement remains insufficient for our purposes.

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[275] Pierron, Jean-Philippe. 2006. *L'engagement. Envies d'agir, raisons d'agir. Sens-Dessous* N° 0 (1): 51–61.
[276] *Ibid.*

1.8.5. Patient Partnership

The final idea that we will investigate is patient partnership. The patient partnership (PP) approach has been developed and advocated for by the University of Montreal. It has an ambitious aim: to move toward a "patient-as-partner" approach in which patients are 1) actors in the doctor-patient relationship 2) involved in research 3) provide training to health sciences students. They claim that, "*including patients as full partners in the health team entails a significant shift in both medical practice and medical educational cultures.*"[277] The PP approach advocates that a successful doctor-patient relationship involves a partnership, in which patients are recognized as experts. They qualify the doctor's knowledge as, *"informed about diagnostic techniques, the cause of disease, prognosis, treatment options, and preventive strategies,"*[278] and the patient's expertise as, *"experience of illness, social circumstances, habits and behaviors, attitudes to risk, values and preferences."*[279] According to these authors, both types of knowledge are needed to successfully manage illness and both will be equally valued. What this implies is that if both types of knowledge are valued, *"sometimes the best decision for the patient is not to take the medicine prescribed."*[280]

Furthermore, the PP approach means integration of patients not into separate spaces, but into existing healthcare training facilities. The recruitment of these persons is mainly by patients themselves through a recruitment process designed by them. They call this, *"an engaging and highly innovative knowledge production setting, completely integrated into our medical school."*[281] One of the main goals of patient involvement in the medical school is development of *"the first taxonomy of patient competences"*[282] to allow the assessment and monitoring of patients' skills and competences in healthcare settings. Furthermore, in the research sector, PPs has been integrated into counseling and review roles in governmental funding bodies.

The PP approach is highly attractive for a number of reasons: in the first place it seeks to give epistemic credibility to patients as full partners in healthcare decision-

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[277] Karazivan, Philippe, Vincent Dumez, Luigi Flora, Marie-Pascale Pomey, Claudio Del Grande, Djahanchah Philip Ghadiri, Nicolas Fernandez, Emmanuelle Jouet, Olivier Las Vergnas, and Paule Lebel. 2015. *The Patient-as-Partner Approach in Health Care: A Conceptual Framework for a Necessary Transition.* Academic Medicine 90 (4), p. 437.
[278] *Ibid.*, p. 438
[279] *Ibid.* Quoting: Coulter, A., 1999. *Paternalism or partnership?* BMJ 319, p. 719.
[280] *Ibid.*, p. 438.
[281] *Ibid.*, p. 439.
[282] *Ibid.* p. 439.

making. In the second place, it seeks to make a stance on the right of patients to decide what is valuable from their perspective, allowing for a decision-making capacity outside of the biomedical model (i.e. the right not to adhere to their treatment, if the patient decides that this is not in their best interests). The PP program also allows fellow patients to define the methodology for recruitment of other patients, allowing recognition of expertise which is patient-to-patient. It also sees the means for other *types* and *levels* of participation (i.e. in medical training curriculum as well as in research and budgeting discussions within governmental bodies).

However, as is probably obvious from our description, for our purposes the PP model is still insufficient. In the first place, the patient's participation is as a chronic disease patient in the healthcare relationship, and in turn in research and training. At what point does the patient leave the sick role and become a patient with expertise? At what point does the patient become a non-patient once outside of the healthcare act? It is therefore not clear here if we are seeking active patient participation for the patient outside of healthcare, nor what it implies that a patient continues to be a patient, even when recruited as a trainer or in governmental review boards.

In addition, as has already been highlighted in the section on recognition of expertise, despite these intentions, it remains difficult on the ground to understand patients' and healthcare providers' expertise as both equal and fully relevant in the doctor-patient relationship. As already highlighted, since healthcare providers act based on the biomedical model, we cannot guarantee nor expect that they will see the patient's expertise as valuable in the development of the healthcare plan. We do not make a judgment here on whether it is right or wrong to do so, but rather on the practical implications of integrating this expertise, as we have discussed in Biomedical Claim 3. Thus the PP model has not solved the problem of the place of such expertise nor the recognition of such expertise in the healthcare act, or how this expertise can be integrated into research agendas if both patients and healthcare providers participate.

The PP model has however, suggested means of sourcing or valuing this expertise on research agendas, with tools such as online forums where patients are free to speak of their expertise. We will not comment on this method, but we must highlight again that recognition of expertise is coordinated and integrated with healthcare institutions and research agendas. Therefore it does not envisage patient empowerment outside of these cadres, even if it recognizes the valuable role of outside patient experience in developing this expertise. As such the PP model is largely an institutional cadre, which seeks to

expand and find further means for the institutional recognition of patient expertise. It also does not pay adequate attention to the value of empowerment when the patient is no longer a patient. We should also question if patients are even seeking these kinds of (new) roles, and if so, which patients we are even talking about. Giving decision-making power to only those who can communicate easily with doctors or policy makers may also represent a case of epistemic injustice for other patients.

In the various models that we have highlighted, there remain a number of conceptual problems that do not allow us to move forward, in particular, and most importantly to our project, because they have been developed without patients.

1.9. Further Steps

This chapter has been building the blocks that will be used to conceptualize the patient's point of view of patient empowerment. We have listened to the healthcare institutions and healthcare providers by investigating their models, claims, and formulations of patient empowerment on the ground. We have also investigated other propositions for patient empowerment (*empowerment caring*, *patient activation*, *patient engagement*, and *patient partnership*).

These discussions have helped us to see that patient empowerment discussions are knotted together with economic, biomedical, and political ways of seeing our subject, with differing ambitions to make patient empowerment a reality. These discussions have in particular helped us to understand that the biomedical aims of patient empowerment seek greater participation for the patient in order to both (1) develop a more personalized treatment plan and (2) to ensure that patients stick to this treatment plan. The expertise, opinions, desires, and meanings of patients are sometimes, but not necessarily taken into account, especially if they do not harmonize with the biomedical perspective. Still, it is a convincing model as it has as its end point, "better treatment outcomes." Wouldn't the patient also want to have a "better treatment outcome?" and shouldn't he or she participate as the doctor requests as a result? The problem is that patients may not see it this way; they may be looking for another level and another means of participation with their doctor; they may be looking for other treatment outcomes than as suggested in the biomedical model; they may be looking for empowerment outside of the doctor's office, as a person in society. If we accept the biomedical model, what we are saying is that if patients want to participate, they have to participate in a certain way. Therefore, it makes no sense to speak of patient empowerment.

On the other hand, conceiving of patient empowerment in terms of a fully autonomous person is equally problematic. Let us be realistic here: patients who seek out the healthcare relationship are not full actors; at different temporalities, they are also unable or unwilling to be actors at all. In return, the doctor is almost always a full actor, acting on behalf of the patient. This leads us to ask if patients need to fully exit the healthcare relationship in order to be a full actor. This, however, has little practical meaning, as patients seek out the healthcare relationship for problems they cannot solve on

their own. What the discussion around autonomy shows us is that, if in patient empowerment terms, we are expecting a patient to act, they cannot act alone.

However, by focusing on autonomy, we can come to understand that what we are looking for is a way to acknowledge, *"that person's right to hold views, to make choices, and to take action based on personal values and beliefs."*[283] As empowering caring and patient or person-centered care has shown us, we are no longer in a dynamic where it is acceptable to (only) take into consideration the biomedical point of view. This means that the patient's needs, values, and ideas about patient empowerment must now come to the forefront, at least if we are actually serious about making patient empowerment a reality in our institutions, and for the idea to have any meaning for patients themselves. Therefore, what we are seeking is a *patient-developed conception*, proposed by patients themselves, not a patient-centered one in which healthcare providers speak in the best interests of the patient.

As the discussion on other formulations of the patient's participation has shown us, we do not seek to see the patient as a "process" (unless it is part of an ongoing process) or a "quantifiable outcome" to be reached (patient activation), nor do we wish to deceive ourselves that patients are "full partners" in the healthcare act (the patient-as-partner model). Patients are vulnerable, whether or not they have left the sick role. They need and seek assistance, and the reality of that assistance is that at times, they are unwilling or unable to have an active role in the healthcare relationship. Martha Nussbaum's understandings of vulnerability (in relation to emotions and to capabilities) will help us better understand patients in their vulnerabilities and what this might mean to patient empowerment from the patient's perspective. We will see how Nussbaum's philosophy can help us integrate both empowerment and vulnerability in the subsequent chapters of this thesis.

In turn, while patients bring differing values and levels of expertise to their disease management, this expertise has both its place inside and outside of the healthcare act. In a perfect world, it would be possible to integrate experimental knowledge and expertise into the healthcare plan, but the way in which modern medicine is formulated means that piecemeal and individual knowledge must be collated, filtered, and reviewed through the biomedical model in order for it to have a guaranteed impact on the healthcare plan. As

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[283] Beauchamp, Tom L., and James F. Childress. 2001. *Principles of Biomedical Ethics*. 5th ed. New York, N.Y: Oxford University Press. p. 63

such both the patient and the doctor have trouble fitting all aspects of patient expertise in the healthcare act and in seeing their place. Patients are also looking to find ways outside of the doctor's guidance to live with their disease; it should not be taken for granted that they may not even want to share this expertise with their doctor.[284] There is no reason to despair, if we see patient empowerment both in and outside of the healthcare act, and if we welcome the possibility of patients to be seen as persons and to be full actors once they leave the doctor's office. For this to happen, however, we will have to give up some assumptions of the biomedical model and accept that patients will sometimes decide not to adhere to the treatment plan.

If we understand all of these factors, it is not surprising that so far patient empowerment has not had much meaning for patients themselves. Patients I have interviewed in France often have never even heard of the idea (of the term *patient acteur*) even though many healthcare institutions have integrated it in their healthcare plan. In China, the term "empowerment" had to be explained and reexamined, before being dismissed by many patients and healthcare providers as unfeasible when the doctor has only five minutes for a consultation. In its present form, patient empowerment could be a case for *hermeneutical injustice*, as patients do not see the connection between this idea and their experience with their disease.

For the idea of patient empowerment to have any meaning for the patients themselves, for patients and healthcare providers to integrate it, we need to look at what patients want from patient empowerment. We will need to understand what they think is a good outcome and what we can do as societies to enable persons to live well with and in spite of their disease. To accomplish this ambitious task, we will propose our methods *with* emotions and *with* capabilities in subsequent chapters. However, we can already say that our approach follows qualitative methodologies. We have made this choice as qualitative methodologies can allow space for the voices of those who are less represented. [285] Another advantage of qualitative methods is that they can allow divergent and new ideas to emerge, which can have practical implications in the field.[286] Thus, our aim in favoring qualitative

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[284] When discussing this experiential knowledge with patients, they were often surprised when I asked them if they shared this information with their doctor. They often did not see its place in the doctor-patient relationship even though some referred to stress reduction activities (such as sports), as a "type of medication."

[285] Spranzi, M., 2018. *Le travail de l'éthique: Décision clinique et intuitions morales*, Psy - Théories, débats, synthèse. Pierre Mardaga Editeur, Sprimont. p. 131.

[286] *Ibid.*, p. 131.

methods is to allow new ideas to emerge, in particular those ideas directly coming from patients themselves. However, we will not ignore healthcare provider's perspectives on this topic, either. This would be an epistemic injustice in the other direction.

We have developed a list of patients' needs from these discussions to move toward the patient life empowerment approach we will develop in the next chapters. These needs include:

1. To involve the patient in the conceptualization of patient empowerment
2. To envisage a concept which creates the possibility for empowerment but does not impose it
3. To understand patient empowerment's potential both *inside* and *outside* the doctor's office
4. To create a realistic cadre in which the patient can act

Definition of the Field

In order to move toward our patient-developed approach, it is necessary to move into the field and to conceptualize our subject with patients directly. However, if the idea of the field for disciplines such as sociology or anthropology is fairly clear, the space and time for a field philosopher is more ambiguous. To define our use of the field for this project, we will take inspiration from the multi-site method developed in anthropology in the 1990s. While traditional anthropological methods favor the idea of a named field, limited in space (and time), the multi-sited research method developed by Marcus[287] instead allows more flexibility in the idea of the field as multiple spaces and times, or even imaginary fields. It has become a popular approach in anthropology to study cultures and practices in movement (immigration, healthcare journeys…) and suggests that the researcher should also be moving between these sites.[288] In promoting the potential of the multi-site research methods, Falzon[289] suggests that time, but also space, can both *transform* and *make*. It helps us to develop a concept, but in doing fieldwork, it is not necessary to block oneself off from these multiple temporalities and spaces of reflection.

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[287] Marcus, G.E., 1999. *What Is At Stake–And Is Not–In The Idea And Practice Of Multi-Sited Ethnography*. Canberra Anthropology 22, 6–14.
[288] Burrell, J., 2009. *The Field Site as a Network: A Strategy for Locating Ethnographic Research*. Field Methods 21, p. 183.
[289] Falzon, M.-A. (Ed.), 2009. *Multi-sited ethnography: theory, praxis and locality in contemporary research*. Ashgate, Farnham, England ; Burlington, VT. p.8.

In this thesis, we will be describing two methods that we developed to move toward a patient-developed definition of empowerment. One of these methods will be called a method *with* emotions and the other a method *with* capabilities. As we will see, these methods are not opposed: the method *with* emotions, which we will develop first, will be shown to be the first component of our analysis. We will use our method to examine the tensions and suffering which the patient experiences in their daily lives, in order to determine why they are currently unable to be empowered, before moving on to which capabilities patients are seeking. Our methods are thus part of the same ambition. In the next chapters, we will be showing how we developed these methods in multiple spaces and times. However even by making this assertion, we are not describing an exhaustive representation of our field. In the first place, the reflection took place in formal field sites of healthcare delivery, but it also took place in informal conversations with patients and healthcare providers. The reflection also took place in the library, inspired by readings of philosophers, sociologists, and anthropologists.[290] Therefore we define our field as *multiple and dynamic spaces, temporalities, and disciplines of reflection*.[291]

[290] Sociologists point out that multi-sited fields are often fuzzy and not always clearly defined in an easily delimited time or in space. See: Nadai, E., Maeder, C., 2005. *Fuzzy Fields. Multi-Sited Ethnography in Sociological Research*. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research Vol 6, No 3 (2005): The State of the Art of Qualitative Research in Europe.

[291] One of the unsuspected spaces for reflection was during the restitution phase of this research. In *Nature and Experience*, John Dewey says that the problem with philosophy comes when, "*They have failed to return to the context of actual experience, there to receive their check." (*Dewey, J., 1994. *Experience & Nature*. Open Court, Chicago, Ill.; La Salle, Ill. P. 33-34.) The multiple restitutions (with healthcare staff, patients, at scientific conferences, at the university) were this "check" of the realities of the field and my interpretation of it.

Fieldwork in Philosophy

Before moving on to the next chapter, we would like to clarify one final element: the reason why we will do fieldwork to conceptualize this subject. If in sociology, an objective of doing fieldwork may be to understand social processes, a secondary objective is usually to bring a social contribution. However, the objective of the field philosopher remains less clear. Does the philosopher do fieldwork (only) to advance or defend philosophical concepts? Or is the philosopher also looking to make a social contribution through philosophy? John Dewey puts us to task on these questions, by advocating that if a philosophical concept makes philosophy advance, it should also enrich our lives in society. He even presents the following test for philosophy:

> *"Does it end in conclusions which, when they are referred back to ordinary life experiences and their predicaments, render them more significant, more luminous to us, and make our dealings with them more fruitful? Or does it terminate in rendering the things of ordinary experience more opaque than they were before, and in depriving them of having in "reality" even the significance they had previously seemed to have?"*[292]

In Dewey's conception, the first objective of philosophy is not to defend philosophical traditions, but to serve as a guide for society. As we will see, American philosopher Martha Nussbaum has similar aims. Our thesis also aims to unblock a social question. This thesis is therefore an argument that philosophy does have a social contribution to offer, and shows that by going to the field, philosophers can provide a contribution to some of society's questions.

[292] Dewey, J., 1994. *Experience & Nature*. Open Court, Chicago, Ill.; La Salle, Ill. P, p. 7

Choice of Interviewees

Before continuing to Chapter 2, it will be helpful to pinpoint what the choice of research participants will mean to the development of the concepts proposed in this research. For clarity, let us first define epilepsy and in turn refractory epilepsy.[293] The most widely accepted[294] clinical definition of epilepsy is:

Table 2: Definition of Epilepsy

A disease of the brain defined by any of the following conditions:
1) At least two unprovoked (or reflex) seizures occurring more than 24 hours apart
2) One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3) Diagnosis of an epilepsy syndrome.[295]

The seizure is the event, while epilepsy refers to the disease associated with recurring seizures. In order to be diagnosed epileptic, according to the definition cited above, the person must have experienced at least two unprovoked seizures[296], although the time between these seizures can be long (up to 10 years). The various manifestations of epilepsy – and seizures themselves – are highly individual and variable, as well as dynamic. This makes it difficult for clinicians to both diagnose epilepsy, as well as find an effective treatment for each individual case. Most causes of epilepsy are idiopathic. It is also common for only one person in a family to have epilepsy.

The most common treatment for epilepsy is the use of anti-epileptic medication (AEDs) although increasingly there are possibilities to treat epilepsy through surgery and other devices (such as vagus nerve stimulation). Due to the high variability of each person's epilepsy, there is also potential for experimental knowledge to help patients find alternative ways to reduce seizures, including through emotional management, diet changes[297], etc.

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[293] For more information on definitions and related concepts of epilepsy, see the Appendix.
[294] A task force of the International League Against Epilepsy (ILAE) has proposed this definition, and it is currently the most widely used/accepted clinical practice definition.
[295] Fisher, R.S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J.H., Elger, C.E., Engel, J., Forsgren, L., French, J.A., Glynn, M., Hesdorffer, D.C., Lee, B.I., Mathern, G.W., Moshé, S.L., Perucca, E., Scheffer, I.E., Tomson, T., Watanabe, M., Wiebe, S., 2014. *ILAE Official Report: A practical clinical definition of epilepsy*. Epilepsia 55, p. 477.
[296] Although some persons are treated for epilepsy even after one seizure
[297] It is thought that the ketogenic diet can reduce seizures for certain individuals.

Refractory epilepsy[298] is a definition used closely in line with the treatment of the disease. It is defined as, *"the failure of adequate trials of two tolerated and appropriately chosen and used AED schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom."*[299] What we can retain from this definition is that refractory epilepsy implies a non-stabilization of seizures over a long-term temporality (sustained seizure freedom) with available treatments. The main feature of this definition is to emphasize that current treatments for the disease are unable to free the patient completely from seizures.

Borderline cases

As Spranzi elaborates, a case it is not only a story, but one that is chosen for the characteristics that it possesses to enlighten other situations or to help with a more general reflection.[300] In this thesis, we chose to focus on a *borderline case*, refractory epilepsy, which represents the approximately one-third of epilepsy patients that cannot be stabilized with anti-epileptic medications.

It is often that in chronic disease, *"the person who knows best the disease is the patient."*[301] In healthcare discussions in pubic and academic contexts, it is often said that those who have more severe forms of disease (such as refractory epilepsy), or those who require more help to live with their condition, will be more motivated — because they have more reason — to be empowered. However, the weight of the disease on the person herself and the difficulties this entails is not to be discounted. One example is our research site of the Teppe, which is a complicated space where patients have severe forms of epilepsy,

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[298] This is called by various names, including drug-resistant, refractory, uncontrolled, or intractable epilepsy. We prefer the term refractory in this thesis over the other most common formulation (drug-resistant) given the concurrent use of the word drug/medication in English, which may cause misunderstandings to a French reader.

[299] The number of AEDs that should be tried before the patient is considered refractory remains contentious; however, the definition does not seek to promote the idea that the patient will never become seizure-free (given that epilepsy can change in time) nor that further attempts to try AEDs may ultimately be unsuccessful. See: Kwan, P., Arzimanoglou, A., Berg, A.T., Brodie, M.J., Allen Hauser, W., Mathern, G., Moshé, S.L., Perucca, E., Wiebe, S., French, J., 2009. *Definition of drug resistant epilepsy: Consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies: Definition of Drug Resistant Epilepsy*. Epilepsia 51, p. 1069.

[300] As Spranzi points out, cases can serve as arguments or ornaments and proceed by narration. Spranzi, M., 2018. *Le travail de l'éthique: Décision clinique et intuitions morales*, Psy - Théories, débats, synthèse. Pierre Mardaga Editeur, Sprimont. p.106.

[301] Quotation from healthcare provider at the Teppe. Interview conducted in February 2018.

which often cross the border between neurology and psychiatry.[302] Many of these patients have had epilepsy since their childhood or adolescence; many have suffered cognitive as well as educational difficulties because of their disease. Thus, they can either be seen as the ideal case for patient empowerment given the severity of their epilepsy and their long healthcare journey to stabilize their epilepsy, or the limits of the patient empowerment model due to these difficulties.

As we will see in Chapter 3, these borderline cases mean some variations, but not necessarily an in-capability to be empowered, if we can accept that each person will be empowered as he or she is *capable*. By finding out how refractory epilepsy patients, even with severe manifestations of a tricky disease, can be empowered, we can understand the full potential of empowerment. In other words, if it is possible for patients even with complex needs to be empowered, this suggests that it should be possible for patients with less severe manifestations of the disease to do so as well. Thus examining borderline cases can show us the difficulties of patient empowerment — but also its full potential for all types of patients. However, borderline cases also show us the need to solicit and include the patient's perspective in order for it to have meaning for all patients, not just for a select few.

[302] By using the term borderline, we are not aligning with the term "borderline" in psychiatry; while it is true that patients at the Teppe often cross the border between neurology and psychiatry, they are primarily at the establishment to treat their neurological condition (epilepsy) although it is common for patients to benefit from psychiatric or psychological support.

Chapter 2

Relationships of Fear

"Emotions are not like mindless jolts of energy: they focus outward on the world and appraise objects and events in the world."

Martha Nussbaum, *Upheavals of Thought*[303]

[303] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 23-24

2.1. Introduction

As developed in Chapter 1, the objective of the research project was to integrate the patient's perspective of patient empowerment. In Chapter 1, we listened to the healthcare provider's priorities in patient empowerment, but we also questioned the use of autonomy in these definitions. What was missing in these discussions was the patient's perspective on the topic. The remainder of this thesis will move toward a patient-developed definition.

The topic of this research project is interdisciplinary: it could be approached in diverse fields such as psychology or economics. However, this particular project seeks to identify not only how patients live the concept of patient empowerment, therefore of their *actualities*, but also how they could and want to live this concept on the ground, therefore of their *possibilities*. Philosophy gives us this double possibility and therefore remains a vital and pertinent field of study for this ambition. Philosophical inspirations and approaches also opened up possibilities for reimaging the approach which few other fields may be able to do (or at least not in quite the same way), as will be shown through the method proposed for this project.

When considering patient empowerment, it is interesting to understand how these concepts fail on the ground. This chapter outlines a method — and the results from this method — which will conceptualize patient empowerment from the patient's perspective by looking at failures. It will examine what goes wrong for patients right now, in their healthcare and in their overall lives. This is what Miranda Fricker in her epistemic injustice approach calls a "failure-first methodological approach."[304] According to her, in order to identify what positive social situation (an ideal theory) looks like, it is often a good idea to see what counter-pressures the structure needs to remain robust (in other words, to identify the injustice). Non-ideal approaches have been gaining prominence in order to work out the inequalities and discriminations which can only be understood by looking at such imperfect situations on the ground. Non-ideal theories allows us to make comparisons and evaluations, as well as helping us guide actions to move us closer to ideal theories.[305] This chapter uses a failure first methodology to identify what goes wrong for patients in their

[304] Fricker, M. *Epistemic Contribution as a Central Human Capability. I*n Hull, G., 2017. Equal society - essays on equality in theory and practice. p.73

[305] Robeyns, I., Department of Philosophy, Florida State University, 2008. *Ideal Theory in Theory and Practice*: Social Theory and Practice 34, p. 341–342.

healthcare and in their overall lives in order to look at what must change at an individual and institutional level to allow patients to live well. In the final chapter of this thesis, we will be looking in at a healthcare environment which achieves patient life empowerment on the ground (thus showing us a success methodology to identify what has gone well for this institution in the formulation of the patient life empowerment approach).

However, developing an approach from the field remains challenging. In the first place, and as a starting point of this research, it was necessary to find a method that enabled patients to become actors of the subject. In other words, we looked for a method in which the patient was not spoken for but also one in which patients and their families were both able to share — and if possible — to participate in the research itself. This is what Fricker refers to as *epistemic contribution*.[306] We will discuss the possibilities — but also the limitations — that our method allowed in this chapter.

In the first part of this chapter, we will introduce our first research method, a method *with* emotions. This method was inspired by our fieldwork and Martha Nussbaum's philosophy of emotions. Since emotions are also a growing methodological tool in the social and human sciences, sociological and anthropological work on emotions also helped develop this method, in particular by paying attention to the reflexivity and the role of the researcher into the research process. We will outline these ideas and their contributions to our method.

At the end of this chapter, we will develop the reflections that have resulted from this research method. Notably, we will discuss the principle emotion identified through this method: *fear*. We do not consider that fear is unhelpful, or necessarily harmful: instead, we will see that this emotion shows something of importance to the person experiencing or witnessing that emotion. As Hans Jonas expressed it, *"we only know the thing at stake when we know that it is at stake."*[307] The intensity of an emotion such as fear can show us something important in the life of the patient. In inspiration of Nussbaum's philosophy of emotions, what we will be most interested in is what this emotion may be able to show us about the person's *eudaimonia*.[308] We will investigate the various manifestations and

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[306] Fricker, M. *Epistemic Contribution as a Central Human Capability.* In Hull, G., 2017. *Equal society - essays on equality in theory and practice.*

[307] Jonas, H., Greisch, J., 1991. *Le principe responsabilité: une éthique pour la civilisation technologique*, Passages. Éd. du Cerf, Paris. p. 49.

[308] Here we will follow Nussbaum's translation and spelling of eudaimonia to refer to the ancient Greek concept which she translates as *flourishing*. Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 31 footnote 23.

relationships of fear in the life of the patient, of their convergences across sites and countries, in order to see what is blocking the person with epilepsy from flourishing. At the end of this chapter, we will see how this method has moved us closer to the patient life empowerment approach.

2.2. A Method *With* Emotions

In this section, our research method *with* emotions will be described. This method was inspired from the fieldwork developed for this research project and by readings of Martha Nussbaum's philosophy of emotions. Our method *with* emotions consisted in five stages of data gathering and analysis. Table 1 highlights the research stages:

Table 3: Stages of the Research Method with Emotions

Stages	**Content**
1. ***Focused ethnography stage***	Paying attention to recurrent words expressed by research participants
2. ***Interview stage***	Verification and further development of recurrent themes identified in the focused ethnography stage through patient and healthcare provider interviews and new theme identification
3. ***Toward epistemic partnership***	Development of alternative methodologies to allow epistemic partnership between research participants and the researcher
4. ***Seeking convergence***	Verification of the salience of these themes across sites
5. ***Analysis***	Analysis of research findings

2.2.1. Focused Ethnography Stage

In this first stage of the research, a focused ethnography approach was used. Focused ethnography is an applied form of ethnography that explores one particular problem or topic.[309] The scope of focused ethnography is narrower than other forms of ethnography, and the researcher generally relies less on long-term immersion[310] by focusing on a specific problem. The specific problem I sought to investigate was of course, the idea of patient empowerment, having conducted a preliminary investigation of the topic through review of international literature. The short duration of this stage of the research was completed by data collection and analysis via interviews.

[309] Bikker, A.P., Atherton, H., Brant, H., Porqueddu, T., Campbell, J.L., Gibson, A., McKinstry, B., Salisbury, C., Ziebland, S., 2017. *Conducting a team-based multi-sited focused ethnography in primary care.* BMC Med Res Methodol 17, p. 139.
[310] Rashid, M., Hodgson, C.S., Luig, T., 2019. *Ten tips for conducting focused ethnography in medical education research.* Medical Education Online 24, 1624133.

I used focused ethnography as a first step in my research, as a means to better understand the healthcare environment and to witness how actors (healthcare providers, patients) discussed patient participation and healthcare provision. My aim was to better inform myself on the topic from the perspective of the actors and in the context of their environment. Focused ethnography was used at three principal sites in France: two epilepsy patient association groups and one medical-social center specialized in epilepsy patient care. The patient association groups were located in Lyon and Grenoble. I attended their monthly meetings for a period of one year (September 2017 – September 2018) as a participant. I principally observed the discussions, although I introduced myself at each meeting so that participants were aware of my role.

At the medical-social center (La Teppe), I spent several full days in three hospital services shadowing healthcare workers (spending all or part of the working shift with those professionals), observing informal conversations between them and other workers and in their interactions with their patients. I also attended several informal and formal multidisciplinary staff meetings as well as participated in workshops organized at the site (such as the writing workshop). This focused ethnography took place during my overall research stay (February - May 2018), during which I also conducted interviews with patients and healthcare providers in the services that I had observed in these multiple spaces and temporalities. I also spent several half days witnessing consultations given by a neurologist at the center in order to have a better idea of what happened during these consultations and who was present (doctor, patient, family, social educators, etc.)

This research also took place in China for one month in June 2018. However, given the limited research timescale, focused ethnography was only possible in limited ways, notably as a way to better understand epilepsy patient care in the country. This included observing the everyday working environment in rural clinics in Sichuan Province for one day before/after/during interviews with the doctors, as well as one afternoon spent at a hospital in Shanghai[311] with a neurologist in order to understand epilepsy patient consultations in the Chinese context. This limited capacity for ethnography in this second site had an influence on the research results, as I will explain in the next section.

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[311] Shanghai Children's Medical Center-上海交通大学医学院 [WWW Document], n.d. URL https://www.shsmu.edu.cn/english/Affilated_Hospitals/Shanghai_Children_s_Medical_Center.htm (accessed 8.21.19).

Focused ethnography was therefore used in this research project as a form of pilot testing[312] to clarify ideas surrounding patient empowerment in the field from relevant actors before engaging in interviews with participants. This first focused ethnography stage permitted rich contextualization of the specific sites and their assistance to patients, as well as how patients navigated these sites. Even though my topic of interest was determined in advance, the focused ethnography stage allowed new ideas to emerge that would not have been identified via bibliography alone, in particular the predominance of fear.

The first site

It is worth describing in detail the first site where I conducted focused ethnography, as it inspired the method *with* emotions I use in this chapter. This first research site was a patient group consisting of around ten patients or family members that meet several times a month in the locales of a newly established epilepsy center in Lyon.[313] I followed this group for one year (September 2017 – September 2018) by attending their monthly patient group meetings and listening to what patients and families had to say about their epilepsy, their relationships with their healthcare providers, and other subjects of concern to them. The group usually has new persons who have heard about the group through their doctor or other patients; however, there is also a fairly stable following of regular patients or family members who join the group for these meetings. The group usually consists of adult patients and their families and is led by a patient with refractory epilepsy working at the center. While patient groups vary in their focus and their missions[314], the fact that the group is led by a fellow patient without an explicit patient association label means that the subjects discussed are relatively diverse and open. The leader usually proposes a topic he wishes to discuss, although other patients and families are welcome to propose other topics. Often the conversation evolves during the session toward common difficulties in the lives of individual patients and their families. While the discussion is led by the patient facilitator, all participants are invited to speak. The discussions generally last about two

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[312] Savage says that ethnography can be useful to "pilot test" a subject, particularly when the topic is unfamiliar or complex. See: Savage, J., 2006. *Ethnographic evidence: The value of applied ethnography in healthcare*. Journal of Research in Nursing 11, p. 387.

[313] IDÉE Research department, 2015. IDÉE epilepsy institute. URL http://idee-epilepsy.org/2015/11/30/idee-research/ (accessed 3.25.19).

[314] The difference with this site and the patient association meetings in Grenoble, France, was that the Grenoble group was associated with the nationwide French patient association, Épilepsie France. Meetings followed a more formalized structure in line with the association activities. The leadership of this group also had close contacts with the university hospitals and was part of their patient empowerment programs.

hours and usually start with a presentation of new and old members, in which patients describe their epilepsy and various medical and social difficulties of living with the disease. They then continue onto a specific theme or to specific questions or concerns.

This particular patient group mainly attracts refractory epilepsy patients. The age ranges from adults at the start of their careers to retired persons who have been diagnosed with epilepsy after their retirement. The group members are diverse in professions and backgrounds. Indeed, about the only factor that these people have in common is their epilepsy, and usually a fairly severe type of refractory epilepsy. However, the members otherwise are as different as is their epilepsy, with different epilepsy syndromes, a large variety of manifestations of seizures, differing side effects or experiences with various treatment options, and similar but different social factors which influence their ability to live well in society with their disease.

Many of the participants — if not all — come to the group for information from other patients and their families (about doctors, about their epilepsy and possible treatments, about administrative procedures…). However, they also come to find fellow patients like them, those who will not judge them for their epilepsy, because non-stabilization of seizures means difficulties in working and education because of memory problems, concentration and other side effects tied to their disease and treatment. They also come to the group because it is one of the only places they are not obliged to hide their epilepsy. However, the participation of patients suffering from psychological difficulties, tied in diverse ways to their epilepsy, makes these meetings quite heavy. The discussions are often personal, even intimate, with narratives relating to their problems at work, to their personal lives, to their relationships with their families and friends, and to their experiences with their neurologist. It is not rare in these meetings for patients to talk about their inability to accept their epilepsy, their inability to date or marry because of their epilepsy, the significant work and educational problems they experience, and sometimes — about thoughts of suicide — because of living with such an unpredictable disease.

The group leader was open to having me come to the group. He also had a personal interest: to have someone — anyone — talk more about epilepsy, in order to raise social and academic awareness about the disease. However, being accepted by the others in the group was difficult.[315] As I came to the group to listen and to better understand epilepsy —

[315] This is what Shaffir and Stebbins call "getting in." The easiest way to "get in" a research site is for the "gatekeepers" and the "researcher" to have similar interests. In the case of this research project, while the

having only an academic understanding of the subject — acceptance within the group was problematic. Each person was expected to speak, to share their epilepsy experience, even to provide intimate and embarrassing details, just as the others had done at some point during each meeting. The idea that a researcher was there to observe these meetings made my presence troubling to those who shared intimate details about their lives. In this situation, it was not possible to take notes, let alone to record the meetings, as it would have bothered the participants. In this constrained space, it was necessary to develop a method that would not bother the participants or make them feel like the object of a study.

Therefore as a first attempt at a method, I decided to mobilize a method popular in anthropology: using *key words*.[316] This method involves concentrating on and committing to memory key words or phrases heard in a setting, enabling the researcher to recall the meanings of their remarks after the event. The advantage is that it allowed me to pay attention to certain words without having to write word for word what participants say. In itself, identifying key words is a fairly intuitive process as often we retain words that interest us in discussions. It also allows for surprises by paying attention to previously unsuspected themes.[317] This method proved to be useful for my reflection, because by coming to the group, listening month after month to these patients and families, I found a word that was voiced again and again, one in which I was to hear across my research sites and in two countries: the word *fear*.

This key word search led to the approach that was the first step in development of my patient life empowerment approach, a method *with* emotions. It was not a question of trying to measure fear, for instance by asking patients when they were scared and why they were scared (to conduct research *on* emotions that some sociological studies of emotions do). On the contrary, it was more interesting to pay attention to when patients used the word and why, to see what this emotion showed about their *eudaimonia*, in inspiration of the philosophy of emotions of Martha Nussbaum. We will examine Nussbaum's philosophy in the next section, including what Nussbaum has to say about that particularly destructive emotion. However, for now, let us see how the method *with* emotions further developed through new methodologies.

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group leader saw a harmony between his mission and my research project, "getting in" with the group participants was more challenging. Shaffir, W., Stebbins, R.A. (Eds.), 1991. *Experiencing fieldwork: an inside view of qualitative research*, Sage focus editions. Sage Publications, Newbury Park.

[316] Taylor, S.J., Bogdan, R., 1998. *Introduction to qualitative research methods: a guidebook and resource*, 3rd ed. ed. Wiley, New York. P. 55.

[317] Similar to phenomenological approaches with the concept of "bracketing."

2.2.2. Interview Stage

I have so far discussed how the method *with* emotions led to identification of the word "fear" as an important theme for my research. However, a potential problem in focusing on an emotion as strong as fear is its predominance, its strong character. In choosing this method, the word that was most shocking was identified. Sociological studies on emotion for this reason show a danger to mobilize emotions in research. These studies say that engaging emotions in research can led to bias due to their strong emotional impact.[318] In these conceptions, emotions are problematic in the sense that they lead the researcher to lose objectivity or distance from the research subject and the research participants. Therefore, emotions are often viewed as a risk.[319]

However, sociological insights also give us ways to work actively *with* emotions by putting the researcher directly in the research process and analysis. More and more sociological researchers see this potential bias in emotions research as an opportunity.[320] Brenton Prosser for example tells us that most research in sociology is orientated *on* emotion and proposes that we work instead *with* emotion.[321] He makes the distinction between the research *on emotion* that sees emotion as a subject of study, by trying to measure or describe aspects of emotion in the same way as other more traditional methods in sociology; and a method *with emotion* that is searching for another type of learning. According to him, research *on emotion* puts the research participant in a passive posture vis à vis the researcher, with a research process that creates or discovers new learning according to data gained from research methodologies. However, a research *with emotion* allows the researcher to understand the process of production as one of co-production with the research participants. For the sociologist, working *with emotions* allows the researcher to explore power relations between the researcher and the participant[322] because the

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[318] Fitzpatrick, P., Olson, R.E., 2015. *A Rough Road Map to Reflexivity in Qualitative Research into Emotions*. Emotion Review 7, p. 49. See also, Kleinman, S. *"Field-workers' feelings."* In: Shaffir, W., Stebbins, R.A. (Eds.), 1991. *Experiencing fieldwork: an inside view of qualitative research*, Sage focus editions. Sage Publications, Newbury Park. p. 184-195.

[319] Hubbard, G., Backett-Milburn, K., Kemmer, D., 2001. *Working with emotion: Issues for the researcher in fieldwork and teamwork*. International Journal of Social Research Methodology 4, p. 119.

[320] Fitzpatrick, P., Olson, R.E., 2015. *A Rough Road Map to Reflexivity in Qualitative Research into Emotions.* Emotion Review 7, 49–54 ; Hubbard, G., Backett-Milburn, K., Kemmer, D., 2001. *Working with emotion: Issues for the researcher in fieldwork and teamwork.* International Journal of Social Research Methodology 4, 119–137 ; Prosser, B., 2015. *Knowledge of the Heart: Ethical Implications of Sociological Research With Emotion.* Emotion Review 7, 175–180.

[321] Prosser, B., 2015. *Knowledge of the Heart: Ethical Implications of Sociological Research With Emotion.* Emotion Review 7, p. 177.

[322] *Ibid.*

knowledge created is not a source of learning coming only from the participants, but rather the result of a co-construction. Working *with emotion* and not *on emotion* allows this space of joint reflection between the participant and the researcher and allows the researcher to look critically on their role in the creation of knowledge. Thus the method developed for this research project has been called "a method *with* emotions."

Given these insights from sociology, I recognized that my first methodology, using key words to identify important words or phrases, was potentially problematic. As the word fear causes fear, it potentially blocked other emotions and important themes by its strong, dominating, and polemic imaginary. Therefore in order to mitigate this potential bias, it was necessary as a second step in the research process to move beyond focused ethnography and to mobilize research methodologies permitting a certain critical distance in the research process and/or greater participation by patients themselves. This was possible via methodologies that could be relistened to, transcribed, analyzed, and questioned once the research process was over.[323]

For these reasons, in-depth interviews were added to this project. The aim of in-depth interviews is to obtain a richer understanding of the topic of interest. Generally, such an approach complements focused ethnographic approaches. In-depth interviewing solicits the participant's experience, feeling, or behavior and combines structure with flexibility.[324] While usually based upon an interview guide, outlining the key topics/questions to be discussed, the structure of the in-depth interview is flexible enough to allow participants to respond to questions in the order of interest to them.[325] In other words, the discussion takes the lead and flows from the responses given by the participant. This type of research method allows participants to articulate their illness experience in their own words and in their own way. Questions are fairly open, but the in-depth interview method also allows the researcher to probe answers given by the participants in order to understand the reasons, motivations, opinions, etc. about the answer given. So for example, if the patient said that they were scared of telling epilepsy to their colleagues (we will see an example of this in

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[323] Notably because retranscription of interviews allows the researcher to see when a question was "leading" or suggested by the researcher, rather than coming directly from the interview participant herself. The first step of the method *with* emotions, by not being able to retranscribe interviews, did not allow this critically needed step-back from the research process. As a result of this critical regard permitted by the interview stage, several interviews were discarded as the researcher saw via relistening that she knew the interviewee too well or because she influenced the responses.
[324] Ritchie, J., Lewis, J. (Eds.), 2014. *Qualitative research practice: a guide for social science students and researchers*, 2nd. ed. ed. SAGE, London. p. 141.
[325] *Ibid.*, p. 141.

this chapter), the researcher can ask follow-up probes such as asking, *Who exactly were they afraid of telling? Why were they afraid of telling? And what consequence did they think telling would lead to?* These probes enabled me to understand underlying issues and other subjects of importance motivating such emotions.

Another important feature of in-depth interviewing is its interaction. It recognizes that the material developed is a co-construction between researcher and participant (the method *with* emotions that Prosser described) given its relatively open format. This co-construction is taken into consideration in the analysis phase.

French Research Stage

The in-depth interview stage of this research was first pilot tested with two patients who expressed their willingness to be interviewed during patient group association meetings. These interviews were conducted in October 2017 and January 2018 in Grenoble. The interview grid was at this stage narrowed from 7 to the 2 principal questions. It was found in the pilot phase that these two questions (in particular the first question) was broad enough to solicit the patient's view on issues as diverse as their family, their education, and their workplace. The second question, however, remained problematic and did not solicit much discussion on the part of participants. Still, as I will highlight in Chapter 3, it was necessary to ask patients this question directly to solicit their perspectives on the subject. In line with the overall research project (for which the same methodology was also used for Chapter 3 of this thesis), the interviews were therefore focused on two principal questions:

Question 1: Please tell me about your epilepsy?
Question 2: What do you understand by patient empowerment?

Follow-up probes were asked depending on this first response, including asking about their opinions and feelings about their medical care, their family environment, and what patients wanted to achieve in their lives despite their epilepsy. However, the first descriptive question was often enough for patients to speak during the entire interview.[326] In the analysis phase, as well as during the interview itself, I paid particular attention to

[326] Descriptive questioning allows participants to describe the experiences, places, people, etc. which come to mind when they think about their disease. See: Taylor, S.J., Bogdan, R., 1998. *Introduction to qualitative research methods: a guidebook and resource*, 3rd ed. ed. Wiley, New York. p. 89.

what sprang to mind first when I asked these questions. Indeed, as will be more fully understood in the last part of this chapter, the results of social stigma due to epilepsy was often the first thing discussed by the participants, not their medical care as I had expected. This was the first time I started to question whether patient empowerment should be situated in the patient-doctor relationship, or whether it needed to be opened to the wider relationships in the person's life.

Given the key word identified in the first research site through focused ethnography, I also paid attention to what emotions (notably fear) were expressed when speaking of these events. I then led or followed-up the questions with probes to understand in greater detail or to clarify what was expressed when they told me they were scared about some situation or person.[327] The interviews confirmed the predominance of fear as a blocking factor for patients to live well with their epilepsy, not only due to its repetition across interviews but also because patients themselves often discussed this emotion in multiple contexts (with their family, with the doctor, in society…). This methodology also gave me the means to better understand this fear in terms of the relationships in their lives.

The pilot phase prepared the 4-month research at the Teppe, a medical-social center specialized in epilepsy at Tain-l'Hermitage (February - May 2018), where interviews were conducted across three hospital services with 19 patients[328] and 10 interviews with healthcare providers, following the focused ethnography stage already described. The patients and healthcare providers interviewed were sourced using a snowball methodology.[329] Interviews lasted from 30 minutes to 1.5 hours, depending on the level of

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[327] This also enabled me in the analysis phase to determine when I had led questions/responses, and thus to discard those responses which were led by myself rather than the participants.

[328] At the Teppe, it was necessary to consider how to establish real consent of the participants. It did not make any sense to have all participants sign a consent form, as many patients often need help reading letters, doing administrative paperwork, etc. I therefore followed a *millefeuille* consent method. In the first place, the healthcare personnel did preparatory work by explaining my presence and why I wished to interview them. Following this discussion, some patients volunteered or were solicited by the personnel given their availability or because healthcare providers thought they would be willing to participate. Because of this selection by healthcare providers did not necessarily guarantee patients' consent, I also asked patients before the interview if they wished to participate, what this involved, and whether or not I could record their conversation. Despite these multiple layers of consent gathering, I do not claim that fully informed consent was achieved. For instance, it could not be confirmed whether participants understood that certain results could be used by the healthcare institutions, or in future articles, as they had limited conceptions of research and how it was used. At the time of writing, I am in discussion with the Teppe of how to restitute the results to patients in an accessible way.

[329] This method identifies research subjects through other research subjects. Patients were sourced by healthcare providers who recommended certain patients to be interviewed based upon being able to adequately communicate with the researcher and/or being well enough (psychologically and physically) to participate. They were not necessarily those who agreed with their treatment plan or had a positive experience at the Teppe. Healthcare providers were primarily identified in the service in which patient

engagement and involvement of participants. Interviews were recorded and transcribed with the consent of the participants, as well as to critically investigate my participation in the research process. The interview transcriptions were then anonymized. During the interviews and ethnography stage, I kept a notebook of key words expressed, the context of the interview, as well as surprises. This research site was the main inspiration for the development of the patient developed approach, as I will discuss in Chapter 3.

As the focus of my research was patients' definitions of empowerment, the patients interviewed served as the principal source of knowledge. The healthcare provider interviews served a more mixed function. In the first place, I was interested in how they conceived of patient empowerment. This was both to understand the conception from their perspectives, but also to compare it with patients. These interviews also permitted me to clarify certain details that had come from the patient's interviews. However, as will be discussed, their responses did not only serve as clarification or comparison, because they also helped me understand their own emotions experienced in the healthcare relationship.

In general, healthcare provider interviews were generally shorter than patient interviews, given the busy schedules of the healthcare providers and generally lasted about 30 minutes. These interviews were recorded and transcribed to permit contextualized analysis after the interviews. Given the diversity of the medical-social center's services, healthcare service providers included four doctors (3 neurologists and 1 psychiatrist), but also nurses (1), current management (3) and social educators (2). Unlike in the patient interviews, the question on patient empowerment was often sufficient as a springboard for healthcare providers to discuss it, their relationship with patients and colleagues, and the role of the institution in promoting it. This again suggested that it has meaning for those who create and mobilize it, rather than those who are said to benefit from it. Interviews with healthcare providers consisted of two principal questions:

Question 1: Please tell me about your work at the Teppe?
Question 2: What do you understand by patient empowerment?

As with patient interviews, probes were used at various times of the interview process to help understand the motivations, feelings, and opinions of the participants.

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participants were interviewed; neurologists and psychiatrists were recommended by my main contact at the site, another neurologist. For more information on snowball sampling, see: Lewis-Beck, M., Bryman, A., Futing-Liao, T., *Snowball Sampling*, 2004., in: *The SAGE Encyclopedia of Social Science Research Methods*. Sage Publications, Inc., 2455 Teller Road, Thousand Oaks California 91320 United States of America.

During the analysis stage, it was necessary to analyze healthcare providers and patients separately, in order to avoid the predominance of the healthcare providers' views, in particular as their understanding of patient empowerment was more clearly defined.

Chinese Research Stage

Following these French research sites, for one month, in June 2018, the same in-depth interviews were conducted in Shanghai, China. The 10 patients interviewed were all sourced from Shanghai's Huashan Hospital.[330] Except for one patient sourced from the outpatient clinic, they all came from the hospital's informal "Seahorse Club" which provides therapeutic patient counseling as well as social activities for epilepsy patients. Six interviews with doctors (4 generalists in a rural area of Sichuan Province and 2 neurologists at Huashan hospital in Shanghai) were also conducted to better understand epilepsy patient care in rural and urban areas.[331] In China, although the interviews were recorded, the information related to the researcher was a summary rather than a direct word-for-word translation of what the patient said. Therefore, these interviews were constructed exclusively as narrative case studies post-interview.

Research Populations across Sites

At the medical-social center of the Teppe, 13/19 of the research participants were in the age range of 20-25. This was a reflection of the specific healthcare plan of the establishment, which mainly takes young adults. In China, however, the research group was slightly older. While age differences were investigated in the analysis, age was not found to be the main criteria affecting patient responses. Instead, the severity of the epilepsy, the moment in which epilepsy was discovered, and the reception of their epilepsy by their families and society was found to be a more important factor than age. It was also not relevant to distinguish in these interviews according to the education level/profession, as many of these patients were unable to work due to the refractory nature of their epilepsy

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[330] Huashan Hospital [WWW Document], n.d. URL http://www.sh-hwmc.com.cn/html/b3a197e91f274091a44e88a26bf52ddc/en/enindex.html (accessed 8.18.19).

[331] While I also conducted 5 interviews with patients in Chengdu, Sichuan Province, I decided to disregard these interviews as they were in simultaneous translation with a neurologist. After several interviews, I realized the doctor was telling me his "analysis" of their epilepsy rather than directly translating the participant's responses. There was thus no way to tell which the patient's and which was the doctor's expertise.

or their inability to find an employer that would accept them. The table below summarizes the research population across sites:

Table 4: Research Population Interviews

France	*China*	*Gender*	*Age*	*Total*
19 refractory epilepsy patients (Tain-l'Hermitage)	10 refractory epilepsy patients (Shanghai)	France: Male: 8; Female: 13 China: Male: 2; Female: 8	France: 20–25 (13); 30–45(2); 45–60(4) China: 30–45 (4); 45–60(6)	29 patients
10 healthcare providers (neurologists, psychiatrists, nurses, social educators	6 doctors (4 generalists in rural areas of Sichuan Province; 2 neurologists in Shanghai)	France: Male: 5; Female: 5 China: Male: 4 Female: 2	N/A[332]	16 healthcare providers

As I will discuss in the last part of this chapter, during the research project, I only conducted one official family member interview (in Lyon in September 2017, identified through the Grenoble patient association). Given that patients themselves were the main focus of my research project, they were prioritized for the interviews. However, family views were solicited through the focused ethnography stage through family member participation in patient groups in Lyon and Grenoble. These observations helped me to develop the family life empowerment approach that I will introduce in Chapter 3. However, for the most part, I rely on the interviews from patients. This is a limitation of my research project and will need to be further explored in subsequent research.

Limits of Patient-Researcher Collaboration

A research process in any form is a certain construction: in the case of this project, I was given the themes to develop for the research by the participants through focused ethnography and in-depth interviews. Once the research period ended, it was up to myself as a researcher to create meaning from this data. For this reason, I sought a third

[332] I did not solicit this information from healthcare providers during the interview stage. At the Teppe and in China, many patients said their age spontaneously during the interviews; thus I was able to collect this information more freely than from healthcare providers.

methodology, which will be highlighted in the next section, which enabled participants to participate more actively in the production of knowledge.

However, for now, let me highlight to what extent each site and/or participant in this research project was an epistemic partner, with the identified theme of fear. While fear was already apparent from the first site studied (the patient group), it was expanded through the multi-site perspective with patients, families, and healthcare providers. However, the research in France gave the foundations for the research conducted in turn in China given its depth, but also its temporality (it was done first). Research in France took place over a period of one year before continuing onto the next site (China) and continuing upon return. The same methodology was used in China, although adapted to the local context, time constraints, and language differences between the two countries. However, the level of interaction or dialogue between the sites remains discordant, which meant that the French site had more influence than the Chinese site.

Given the research timescale in France as well as the focused ethnography stage, it was possible to get to know patients and healthcare providers across different spaces within a particular site, which enabled a rich contextualization before the interview took place. In China however, interviews were largely conducted with strangers that had agreed to come to be interviewed. While the same interview structure gave the opportunity for free discussion, I had fewer contexts to understand the research participants. In addition the research was conducted through translation, providing an additional researcher-participant barrier. The translators were student doctors, who had a prior relationship to the participants interviewed and could share the wider context of the patient in the hospital (in the other spaces of patient care, notably the informal hospital association or in the clinic). However, the go-between of researcher-translator-participant provided an important distance between the two epistemic partners, as well as a potential conflict of interest, as the translators, although students, were represented by the hospital, which meant that they had an *epistemic hold* on the information transmitted.

The result of the uneven temporality, depth of the research, as well as methodology used was that while I had greater confidence in the theme of fear as an important topic because of its predominance in two very different healthcare environments, this also meant that the ideas developed from the second site allowed new inspirations and a deepening of the ideas developed at the first site rather than the other way around. As the anthropologist

Hage notes, with time, the field site becomes "thicker and stickier"[333] and thus harder to disengage. While a multi-sited research approach allowed me enough flexibility to allow new elements of reflection into the overall ideas collected from the first site, the themes developed were principally rooted in the first site. Multi-sited research suggests the researcher be *on the move*[334]*;* however, I could not avoid being — if not physically bounded — thematically rooted to the first site. As the anthropologist Marcus has noted, the work at the second site always "had the first site in mind,"[335] even while investigated independently and for itself.

Thus, I do not neglect that most of what has been developed for this thesis is largely the result of the French site research. I have integrated the Chinese sites as much as possible, given the multiple convergences with the French sites in this chapter, as the common theme of fear was identified in the Chinese sites and in the French sites. However, by consequence, most of the results highlighted in this thesis are from the French site research. In Chapter 3, in particular, I will rely on the data gained from the medical-social center of the Teppe for development of the patient life empowerment approach. I have not given this French site more weight because it is the "French site" but rather because of the depth of the research — and engagement with the participants — was more participatory and in-depth, allowing more themes to emerge. As this engagement involved greater reciprocity (as I will highlight in the next section), I also had greater confidence in the knowledge coproduced (between myself and the participants) than in the Chinese site.

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[333] Hage, G., 2005. *A not so multi-sited ethnography of a not so imagined community*. Anthropological Theory 5, p. 465.
[334] Burrell, J., 2009. *The Field Site as a Network: A Strategy for Locating Ethnographic Research*. Field Methods 21, p. 183.
[335] Marcus, G.E., 1999. *What Is At Stake–And Is Not–In The Idea And Practice Of Multi-Sited Ethnography.* Canberra Anthropology 22, p. 8.

2.2.3. Theater: Toward Epistemic Partnership

Having gone through this research process involving both focused ethnography and interviewing, I realized that I still needed to invest in a method that would allow participants to have greater say in the production of knowledge. The anthropologists Holmes and Marcus give us the idea of *epistemic partnership*, by which they mean a process in which the researcher and the research participants work together, "*risking collaborative encounters of uncertain outcomes for the production of ethnographic knowledge.*"[336] The idea of epistemic partnership shows a certain liberty but also difficulty as both the researcher and the participants are involved in the process of discovery. This is both an advantage and a constraint. The difficulty is that it may lead the research into many, disparate directions. The advantage, however, is that it can also allow unsuspected themes to emerge.

In the spirit of epistemic partnership, and as another way to work *with* emotions, I worked with the patient group described at the beginning of this chapter from November 2017 – February 2018 to create a forum theater show about their lives with epilepsy. Forum theatre is an interactive methodology that aims to involve non-professional actors to develop and rectify the oppression experienced in their daily lives.[337] The process consisted in development of a short play of about 10 minutes about living with epilepsy and ends in a situation of conflict. The play is initially shown to an audience, and is then replayed, and a member of the audience is allowed to step in replace one of the characters in order to resolve the conflict.

A patient originally proposed the idea of forum theatre during one of the patient association meetings. A small group of myself and four other patient actors was formed. With funding from the national patient association, Épilepsie France[338], we were able to hire a professional actor from the Lyon theatre association Pied Levé[339] to help us create a play about patient experiences. I participated as a fellow participant in this play creation, which included identifying themes of importance to all of us (as patients) through

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[336] Holmes, D.R., Marcus, G.E., 2008. *Collaboration Today and the Re-Imagination of the Classic Scene of Fieldwork Encounter*. Collaborative Anthropologies 1, p. 84.

[337] The methodology is called by various names, "forum theatre," "interactive theatre" or "theatre of the oppressed." It was developed by Augusto Boal. For more information, see: Boal, A., 2008. *Theatre of the oppressed*, New edition. ed, Get political. Pluto Press, London.

[338] Accueil - Epilepsie France [WWW Document], n.d. URL http://www.epilepsie-france.com/ (accessed 8.30.19).

[339] La compagnie du Pied Levé | Le théatre, outil pour une transformation sociale, n.d. URL http://www.piedleve.info/ (accessed 8.21.19).

interactive games and discussion, and ending with a final written play production. We showed this play for the first time at the International Day of Epilepsy in February 2018 in Lyon for interested patients, families, and healthcare providers. The play was also shown a week later at a church in Lyon. The play was also shown to future medical students from France, China, and Canada, as part of the summer school of "Humanités et Médecine" held at University Lyon 1 in June 2018, and again at the International Day of Epilepsy in February 2019. The theatre troupe is, at the time of writing, planning future interventions to raise awareness on epilepsy using this methodology.

The play allows patients to engage with their disease in new ways. It encourages new interactions between healthcare professionals and patients, as shown by patient participation in the summer school for medical students. However, it was also a method insightful for my own research process, as it allowed patients to become epistemic partners in the production of knowledge. It was the patients themselves that decided what the themes would be and how to play these themes; thus the participants became both the creators and those that act on that knowledge (they became actors in both senses of the term). Although the professional actor helped us develop and first show the play, it continues today due to the willingness and engagement of the participants. For myself, this method was a way to work in equal partnership with participants, but also to work *with* emotions in a phenomenological way, leading to new reflections on the emotion of fear.

The ten-minute theater show that resulted from this co-creation takes places around a birthday celebration (see Appendix for the full version of this play in French and in English). The play speaks of emotions, circumstances, and situations in which the person is confronted in daily life, factors which block them from living well. Family members, as well as work colleagues, have come to the party. One of the family members is a healthcare professional, who thinks she knows all there is to know about epilepsy and uses her knowledge to paternalistically advise her family member. The other two are working colleagues who make the person suffer from their ignorance and misunderstanding. Thirdly, there is a family member, who is supportive of their family member, but does little to defend their family member from the other oppressors. From the themes developed by the patients, we can see difficulties identified by the patients in their family relationships, in their workplaces, and with healthcare professionals. A common theme among these relationships is again, fear.

Fear surfaces in two ways during the theatre piece. The first is indirectly, in the way that the family members advise the person with epilepsy to avoid risks, showing an

example of overprotection (a theme that we will develop later in this chapter). For instance, one family member emphatically tells her relative with epilepsy: "*No alcohol, no swimming without surveillance, especially you can't drive. You know that you can have a seizure anytime, so pay attention to yourself!*[340] While fear is not specifically named in this story, we can understand through the theatre play that the relative is trying to protect their family member, as they are scared of what could happen when they have a seizure. She therefore encourages her to avoid certain risky behaviors, but also puts additional pressure on her family member to "pay attention to yourself," adding on to the fear already experienced by the patient.

The second time fear resurfaces is at the end of the play. It is an evident instance of fear, in which colleagues refuse to touch the person due to fear of contagion:

- *Nathalie (colleague) : You know in history, we thought they were possessed, those who (she mimics an epileptic convulsion), personally I don't believe it, but there is maybe some truth in that…*
- *Corinne (colleague): Really?*
- *Nathalie : Pierre, isn't it contagious, your thing ? Because I looked it up, on the Internet and also asked some friends. They told me that it could be caught….*
- *Corinne : Really, it's contagious? Oh no…I catch everything that goes around right now. Here, Pierre, your gift.*

Corinne tosses her gift to Pierre and steps back to avoid contact.

The theatre production therefore showed at least two instances of fear in the life of the person with epilepsy, one with family members and another with work colleagues. This method gave me greater confidence in the identification of fear as important for persons with epilepsy, where they experienced that fear, and what actions it led to, because it was the patients themselves who developed these themes during the play creation, by relating what bizarre situations and experiences they had lived through due to their disease. It therefore echoed the experiences and relationships of fear that patients identified through the other stages of the research project.

[340] My translation of the theatre piece (French – English) developed for Chinese participants in the summer school. For the entire text, see the Appendix.

Another unexpected result that came from this method was that it allowed me, as a researcher, to see and to live the subject as a patient, through play. Here the phenomenological experience of emotion with the body came to the forefront. By playing certain characters in the scene, for instance the family member, the person with epilepsy, or the work colleague, it was possible to take the place of these persons and to live how epilepsy affected them both in a cognitive and bodily way. For instance, when I took the place of the person with epilepsy in the scene, a scene in which the patient is neglected and ignored, and the other persons present speak *for* the person (a situation which happens frequently in the life of the patient with epilepsy), I was able to live this experience with and via the body, in turn living the suffering and emotions experienced by the person. The emotions experienced by the participant were no longer those told to me by the patients; they were my emotions. At the end of the theatre piece, when I took the place of Pierre, I experienced in a bodily way what it meant to try to enter into interaction with my colleagues and to be avoided due to fear of contagion.

It would not have been possible to fully live the character in the scene by only saying the lines: it was also necessary to follow the lines with body movement: a sloping of the shoulders, a hand on the forehand, looking at the person with sadness or fear, etc. All of these bodily experiences put a physical weight on the experience. I lived the scene in a cognitive way, by listening and evaluating what the characters said about me, but I also lived it in a bodily way, with my gestures and others' gestures toward me. For instance, when the characters turn away from the person with epilepsy, to talk about her without her involvement; when the conversation happens over the person with epilepsy, suggesting by their bodily movements that the person is "invisible"; and when the characters refuse to touch the person with epilepsy (due to fear of contagion), all of these bodily movements make the actor in the scene experience these emotions with their body, and to respond in a bodily way to these movements. Living this scene cognitively, bodily, and in the environment therefore allowed me to experience how the body helped evaluate the object.

While this kind of research methodology is an evident co-construction of knowledge between the researcher and the participant (research *with* emotion as Prosser has highlighted), it also shows a way to transmit knowledge between the participant and the researcher. This knowledge transfer is textual (via the play produced) but it is also phenomenological. This transfer is in turn both cognitive *and* bodily, and the evaluation of the emotion's salience is both with the violent words said by the other characters in the scene, but also by the violent bodily gestures that these characters exhibit toward the

person. This phenomenological production of knowledge from the field became an important part of my research analysis, providing a critique to Nussbaum, as we will discuss in the next section. The benefit of this research method therefore consisted in both the use of the text created, as well as the phenomenological experience lived through play.

2.2.4. Seeking Convergence

Focused ethnography, in-depth interviewing, and theatre were the three methodologies used for this research project. The two other stages of the method *with* emotions consisted in convergence and analysis of the research results. The research project was *toward convergences*, by which we mean that we sought to identify the common themes present across sites, rather than seeking another shade of analysis such as comparison. From the Latin *convergere*, or "to incline together," along with *com* "with, together," convergence allows the idea of a movement, of bending, turning, or tending toward. Convergence implies bending toward a common goal, narrowing the perspective or the "space between" to allow a common direction in the research. This action of turning *toward* is both an act of exclusion and inclusion, moving research from a method of discovery to one of construction by the researcher.[341] In this section, we will be discussing what a move *toward convergences* brought to this research project. As already discussed, the research took place in France, but also in China, and in multiple informal and formal sites of care.[342] It is worthwhile investigating both the potentialities and difficulties of seeking convergences from such different healthcare environments.

To start this discussion, a move toward convergences in multi-sited research does not give a straightforward methodology to be followed. However, the methodological design of this research project in two countries stemmed from the idea of being able to also divorce the patient experience from its infrastructure and location. The idea was to allow a wider picture to emerge of the shared experience of the condition, in particular what emotions they shared with other epilepsy patients across sites, regardless of a particular healthcare environment or variances in healthcare options and treatments. Here I again

[341] Burrell, J., 2009b. *The Field Site as a Network: A Strategy for Locating Ethnographic Research*. Field Methods 21, p. 182.
[342] By informal sites of care, we refer to patient associations/meetings/groups; by formal we mean mainly hospitals.

found that the emotion fear was one of these pervasive words, present at all sites, suggesting a shared lived experience of the disease.

However, while the themes developed for this research were a result of both one site (the first site as explained in development of a method *with emotions*), this understanding was not discoverable only from a multi-sited perspective. Its presence across sites suggests that it was both discoverable in each site and that its salience beyond an individual site was confirmed only once it was discovered in other sites. As discussed in the previous section, the theme of fear was prevalent in epilepsy during the site research from all directions and experienced by patients themselves in multiple sites and ways in their daily lives. It was discoverable at individual sites, but was also in all sites. Patients themselves openly used the word fear when discussing their disease, their relationships with colleagues or in their family, in ways remarkably similar across cultures.

However, in making this claim I am not saying that fear is a coherent, holistic phenomenon. While similar spaces for fear were identified (the doctor's office, at the workplace, within the family), that does not mean that individuals understood and acted on this fear in the same way, even if, as we will see, the emotion does seem to converge across cultures, encouraging recurrent actions such as hiding or avoidance. Notably, we will need to impose limits on our analysis due to the lessons learned from the constructivist view predominant in sociological and historical studies of emotions, as well as ongoing psychology studies, which show that emotions are experienced, appropriated, and lived to a certain extent in function of culturally normative behavior.[343] What we can retain from these studies is that individual experience of fear may not always be lived in the same way, across cultures or across individuals. For our particular group of patients, the recurrence of this emotion across sites and individuals, in spite of age, background, or culture, and the actions in which this fear seems to encourage does seem to converge across sites, at least for this particular group of patients.[344] Interviewing new groups of patients, with different diseases, in different contexts and cultures, however will lend more weight to whether or not our theme of fear should be limited or expanded.

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[343] For further information, see Lim, N., 2016. *Cultural differences in emotion: differences in emotional arousal level between the East and the West.* Integrative Medicine Research 5, 105–109 and Russell, J.A., 1991. *Culture and the categorization of emotions.* Psychological Bulletin 110, 426–450.

[344] Empirical studies in psychology do show correlations in experiences of fear across Chinese and European research participants, including those fears which have early biological relevance, but also some social fears. See for example: Higgins, L.T., 2004. *Cultural Effects on the Expression of Some Fears by Chinese and British Female Students.* The Journal of Genetic Psychology 165, p. 37.

2.2.5. Analysis

Converging results across sites led to a pre-identification of some recurrent themes that would be further analyzed after the research was completed. The themes developed for this project emerged both from primary (the fieldwork) and secondary material (literature review). The primary material used in the analysis phase consisted in the notes taken during the focused ethnography and interview stages[345], recordings and transcripts of the interviews, and the text and lived experiences of the research play creation and implementation. I followed the intuitive process of thematic analysis described by Taylor and Bogdan[346], which included looking for and investigating themes[347] by examining the data in as many ways as possible. This included reading and rereading the interviews/field notes, relistening to the interview transcriptions, keeping track of ideas/themes/surprises, looking for emerging themes, reading international literature on the topic to spot correlations/variations, etc. The thematic analysis also took into consideration how and in what way the theme was discussed.

Once identified, certain phrases were regrouped and compared to better understand the phenomena, but also to compare contradictory or complementary themes. There was some difference for instance between the interviews of the healthcare professionals and patients, in particular in terms of their visions of "patient empowerment" and in visions of "fear" both of themselves and others. However, once these analyses were complete, I could fully understand just how predominant *fear* was across the research sites and between participants, but also in many contexts in the person's life.

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[345] As suggested by Nowell et al., notes taken during the research process can help record the research process, rationales and researcher's personal reflections to understand their role in knowledge production. Nowell, L.S., Norris, J.M., White, D.E., Moules, N.J., 2017. *Thematic Analysis: Striving to Meet the Trustworthiness Criteria.* International Journal of Qualitative Methods 16, 160940691773384.

[346] Taylor, S.J., Bogdan, R., 1998. *Introduction to qualitative research methods: a guidebook and resource*, 3rd ed. ed. Wiley, New York. p. 130-136.

[347] We also regrouped these themes into capabilities to help us develop the patient life empowerment approach. See Chapter 3 for more information on our use of the capabilities approach as an epistemic tool.

Narrative Cases

As a last step, I constructed a certain number of narrative cases that will be used throughout Chapters 2 and 3 to help illustrate the concepts I am trying to explain. As Spranzi has highlighted, narrative cases show the intimate experience of the disease and its outcome on the person concerned.[348] Having read the interviews a number of times, I began to see that these interviews were "filled with stories" as Byron Good has described in his own research on epilepsy.[349] These stories were often the best illustrations of the approach, in particular because they are situated in their environment, their temporalities, and in their relationships with others.[350] They also allowed me to analyze what was important to patients in these stories through the *narrative emphasis* in these stories and their reasons for telling them in a particular way. This use of narrative cases to illustrate concepts has also been inspired by Martha Nussbaum's use of such techniques. She argues for the use of narrative because of the particularity, emotional appeal, and the plot of narrative gives us a fuller picture of the concept to emerge.[351] A selection of the narrative cases constructed for this project is included in the appendix. As Holly and Colyar have noted,[352] narrative constructs mediate how readers understand a story, allowing the reader to focus on the plot, the persons in that plot, and what is of importance to the story itself. The construction of narrative cases is thus also used in this research project as a means of "storytelling". We will see such narrative cases throughout this chapter.

Constructing these interviews as narrative cases was also a way to honor individual persons' narratives. As Arthur Frank has stated, medical narrative predominates patients' ways of relating their stories. This *narrative surrender* involves not only taking medicines

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[348] Spranzi, M., 2018. *Le travail de l'éthique: Décision clinique et intuitions morales*, Psy - Théories, débats, synthèse. Pierre Mardaga Editeur, Sprimont. p. 111.

[349] Good stated that the interviews were described in narrative terms, as well as filled with smaller stories, as well as at times stories co-related with family members. This kind of storytelling correlates with our findings as well, showing the importance of testimony in these patients' knowledge of their illness (see Chapter 3 of this thesis). Good, B.J., Del Vecchio Good, M.-J., Togan, I., Ilbars, Z., Güvener, A., Gelişen, I., 1994. *In the subjunctive mode: Epilepsy narratives in Turkey.* Social Science & Medicine 38, p. 837.

[350] Although it did not form a major part of my analysis, I also explored some patient autobiographies and works of literature (as part of the overall bibliography) to see if they converged or differed with my research results. These patient autobiographies have been used at some points in this thesis, as the author had a particular clarity or way of expressing an issue which helped to illustrate or explain the concept.

[351] Nussbaum, M.C., 1992. *Love's knowledge: essays on philosophy and literature*. Oxford Univ. Press, New York, NY. p. 46.

[352] Holley, K.A., Colyar, J., 2009. *Rethinking Texts: Narrative and the Construction of Qualitative Research.* Educational Researcher 38, p. 681.

as prescribed, but also learning to tell their story in medical terms.[353] While people still surrender their bodies or diseases to medicine, they also try to hold on to their own stories. Ill people recognize that there is more involved in their experience than this medical narrative can tell and seek to share their own stories of their illness.

However, one problem of using narrative was the multiple possibilities for analysis. As Good stated, storytellings of illness maintain multiple perspectives and the potential for multiple readings.[354] In this research project, it was at times difficult to distinguish the source or meaning of this storytelling: for instance, did the information come from the patient's illness experience or from family or healthcare provider testimony? (we will return to this point in Chapter 3). Was this telling of illness reliable[355], given memory problems of many of our patients? And was the reconstruction of their stories a means to influence[356] or simply to relate their own experience of illness?[357] As my main reason for this construction was to understand why patients told me their stories and in what these stories consisted, I limited my analysis to the narrative emphasis in these stories (whether or not it was accurate). I also did not seek to arrange these narratives into various types of narratives as Frank[358] and Good[359] have done with such illness stories. My main interest was to understand what patients understood as important when they told me their stories.

Contextualizing these interviews into narratives permitted new reflections on the subject, allowing me to better understand the patient's perspective. These reflections will be discussed in Chapter 3, but we can briefly say here that one of these insights was the temporality of the discovery of the disease (related to its cause). While a relative non-important event from the biomedical point of view, knowledge of the cause and the temporality of when the epilepsy first occurred was an important moment in patient narratives, influencing how they saw their disease and their life projects. Formatting these

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[353] Frank, A.W., 1997. *The wounded storyteller: body, illness, and ethics*, Paperback ed. ed. University of Chicago Press, Chicago. p. 6.

[354] Good, B.J., Del Vecchio Good, M.-J., Togan, I., Ilbars, Z., Güvener, A., Gelişen, I., 1994. *In the subjunctive mode: Epilepsy narratives in Turkey*. Social Science & Medicine 38, p. 839.

[355] For a provocative (and infuriating) example of an unreliable illness narrative on epilepsy, see: Slater, L., 2001. *Lying: a metaphorical memoir*. Penguin Books, New York.

[356] This means to influence was to be kept in mind as sometimes patients saw me as part of the healthcare institution, or an "influencer" at the institution.

[357] One of the means of "getting in" at patient associations and hospitals was because many healthcare practioners believe that it does "the patient good" to retell their stories, in particular to strangers. This is also a strategy for overcoming stigmatization of a disease like epilepsy by "daring to tell."

[358] Frank, A.W., 1997. *The wounded storyteller: body, illness, and ethics*, Paperback ed. ed. University of Chicago Press, Chicago.

[359] Good, B.J., Del Vecchio Good, M.-J., Togan, I., Ilbars, Z., Güvener, A., Gelişen, I., 1994. *In the subjunctive mode: Epilepsy narratives in Turkey*. Social Science & Medicine 38, 835–842.

patient stories as narratives therefore added an additional way to analyze the importance of particular events in the patients' lives.

Let us now turn to Nussbaum's philosophy of emotions, which both inspired the method with emotions and its analysis post-research phase. In particular, I used Martha Nussbaum's philosophy of emotions, especially her link between the emotional intensity of a given emotion and its possible relation to the person's *eudaimonia*, to understand just how important an emotion like fear could be to the person's possibility to live well with their disease. Now let us describe Nussbaum's theory of emotions to complete our method *with* emotions and the analysis of these emotions.

2.3. Nussbaum's Philosophy of Emotions

In this section, we will introduce Martha Nussbaum's philosophy of emotions and its reconfiguration for this research project. This includes introducing a hybrid view that takes into account the phenomenological experience of emotions in the body. We will also move beyond Nussbaum's conceptualizations of emotions in development psychology through the input of sociologists. This is necessary to understand how these emotions affect the person with epilepsy in today's societies. This section will also introduce Nussbaum's application of emotions to society's problems, as it is important not only for understanding her philosophy, but also because it aligns closely with our research aims.

2.3.1. Emotions and Moral Life

To start the discussion on Nussbaum's philosophy of emotions, it will be useful to situate her thinking within current philosophical ideas. While philosophers have studied emotions for thousands of years, an increasing interest — and legitimacy—has been shown to emotions for several decades, notably due to new research in the cognitive sciences. This research has provoked a reconfiguration in the idea that emotions imply thinking, judgment, or evaluation. Many philosophers today accept that emotions have a relationship to thoughts, in particular to our judgments.[360] Also there is a general agreement that emotions can be taught, although it is still debate on *if* and *how* emotions should be taught. Still many of these philosophers do agree that emotions can make a valuable contribution to moral life.[361] Martha Nussbaum's contribution has been part of this "emotional turn" in philosophy, investigating what emotions can tell us about how to live.[362]

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[360] Cates, D.F., 2003. *Conceiving Emotions: Martha Nussbaum's Upheavals of Thought*. Journal of Religious Ethics 31, p. 326.
[361] *Ibid.*
[362] Nussbaum's philosophy of emotions has some similarities, but also important differences between how emotions are treated in theories of care. In the most care theories, the specific aim of emotional investigations is to understand which emotions inspire care. However, because of care theory's concern with feminist oppression, there is some reticence to only favour emotions as a basis of moral evaluations. Nussbaum's aim with her philosophy is more ambitious than these theories, as she seeks not only to investigate which emotions inspire care (such as her investigation of compassion), but to understand how emotions are linked to *eudaimonia*. In Nussbaum's theory, the first step is the evaluation of the emotion in relationship to the individual's flourishing, and then, a second step will be to look at how to favour this flourishing. Care theories of emotions thus become relevant in Nussbaum's theory *after* the first evaluation when we look at the social conditions. For a discussion on how emotions have been linked to moral evaluation in care theories, see: Pulcini, E., 2017. *What Emotions Motivate Care?* Emotion Review 9, P. 64-67.

The field of virtue ethics has in particular taken on the challenge of what emotions can contribute to moral life. While virtue ethics is by no means a new moral theory,[363] it has gained increased interest, at least partly due to its ability to be concerned with "a whole life" rather than distinct events or situations in which morality is at stake.[364] In these theories[365], Aristotle's conception of *eudaimonia* has played a leading role.[366] Beginning with the concept of *eudaimonia* changes the starting point for moral reasoning. Rather than asking, *"what should we do?"* it asks, *"what is the best way to live?"*[367] Being able to answer this question requires a global, systemic approach rather than an approach focused on a specific moral action. Virtue ethics approaches thus favor reflection on human characteristics and what sort of a person one should be.[368] Miranda Fricker's epistemic injustice approach contributes to epistemic virtue theory, by understanding what specific virtues we need to combat epistemic injustice.

Virtue theory has correlated with an increasing position for emotions in moral theory. According to Aristotle, virtue is understood as both an intellectual and an emotional disposition.[369] Because virtue represents the human characteristics leading to *eudaimonia*, and as character virtues show themselves in emotions, this means that virtues cannot in turn be understood without emotions. While Nussbaum rejects her inclusion into the virtue theory field,[370] she has proposed a theory of emotions that takes into

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[363] According to Russell, virtue ethics has a longer tradition than any other in moral philosophy, stemming from ancient Greek philosophy and ancient Chinese philosophers. For more information, see: Russell, Daniel C. *Introduction: virtue ethics in modern moral philosophy*. In: Russell, D.C. (Ed.), 2013. *The Cambridge Companion to Virtue Ethics.* Cambridge University Press, Cambridge. p. 1

[364] *Ibid.*, p. 2

[365] Given the multiplicity of theories which have developed from this concept, it is preferable to speak of virtue theories in the plural tense.

[366] However, there are many other ways that virtue theory has been conceived. Among other philosophical underpinnings include other philosophers from Antiquity (Plato, the Stoics…) but also Kant and Hume.

[367] Russell, Daniel C. *Virtue ethics, happiness, and the good life*. In Russell, D.C. (Ed.), 2013. *The Cambridge Companion to Virtue Ethics.* Cambridge University Press, Cambridge. p. 7

[368] *Ibid.*, p. 7

[369] Kamtekar, Rachana. *Ancient virtue ethics*. In Russell, D.C. (Ed.), 2013. *The Cambridge Companion to Virtue Ethics.* Cambridge University Press, Cambridge.

[370] Nussbaum herself takes issue with joining virtue ethics camps as she believes the new trend toward virtue ethics justifies relativism, which she argues is in fundamental conflict with Aristotle's plural notions of human flourishing. This view is open to debate; even Nussbaum admits that writers like Bernard Williams never openly show a relativist view. That said, her theory of emotions can be said to lie in this "school of thought" as she uses Aristotle's idea of *eudaimonia*, although adding several supplements from psychology, cognitive science, and by taking a Neo-Stoic view in order to propose her philosophy of emotions. For more information, see: Nussbaum, M.C., 1988. *Non-Relative Virtues: An Aristotelian Approach*. Midwest Studies In Philosophy 13, p. 33.

consideration the Aristotelian contribution[371] to emotions. However, she has also proposed a widening through what she calls her Neo-Stoic approach. Nussbaum has made an important contribution to the current studies of emotions in philosophy, most notably with her book, *Upheavals of Thought: the Intelligence of Emotions.*[372]

The increasing interest in emotions in philosophy (as well as in human and social sciences) is part of what is often called the "emotional turn." In the preface to his revised 2016 edition of *Descartes' Error*, neuroscientist Antonio Damasio traces the transformation in emotion research in the decade following the publication of his 1994 work as well as key neuroscience works such as LeDoux's *The Emotional Brain* (1996)[373] as "radically different'" to when his book was first published. Since then emotion research has experienced a revival. It was also during this time that those working on the subject in various fields — such as philosophy — were given their full voice. According to Damasio, during this time, *"philosophers cultivating the subject were heard with a new attention…Martha Nussbaum was a particularly good example of this."*[374] Nussbaum's contribution to the field of emotions has largely been recognized both within and without the philosophical community, in a large part due to these new discussions and research fields. Nussbaum's contribution can therefore be seen as part of a wider proposition to find a place for emotions in contemporary moral life. It has its value in both philosophy and applications of philosophy in the field. In the case of this research project, it has proven useful for development of the fieldwork method and its analysis. Let us now describe her theory of emotions and its relevance for our project.

2.3.2. Chosen Works

In order to proceed with our project, it will be necessary to limit the reading in this chapter to a few of her works, as Nussbaum has published a whirlwind of writing, from the classics, going toward her theory of emotions, and cumulating in political philosophy with

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[371] For further information on Aristotle's idea of emotions, see: Fortenbaugh, W.W., 2002. *Aristotle on emotion: a contribution to philosophical psychology, rhetoric, poetics, politics, and ethics*, 2nd ed. ed. Duckworth, London.
[372] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York.
[373] LeDoux, J.E., 1998. *The emotional brain: the mysterious underpinnings of emotional life*, 1st. Touchstone ed. ed, A Touchstone book. Simon & Schuster, New York, NY. p. xvi
[374] Damasio, A.R., 1994. *Descartes' error: emotion, reason, and the human brain*. Putnam, New York.

the capabilities approach.[375] In addition, her work is constantly evolving, as she continues to publish profusely and participate actively in university and in public discourse outside of the university community, although it could be said that her current writings are increasingly focused on applying her philosophy to society's problems[376] rather than proposing new philosophical concepts. She was first inspired and the most profoundly by her readings of the classics (especially Aristotle), but it could be said that her other influences are plentiful: John Rawls, John Stuart Mill, Karl Marx, but also the psychologist Melanie Klein and the neuroscientist Antonio Damasio.

Martha Nussbaum has had a prolific career, only one part of which includes the conceptualization of the philosophy of emotions that we will discuss in this chapter.[377] For our purposes, it will be necessary to limit our readings exclusively in this section to her work on emotions. We are mainly interested in two particular aspects of her work: her Neo-Stoic account as developed principally and most thoroughly in her book *Upheavals of Thought*, and her application of her theory of emotions to society's problems, which can be seen in diverse works following this first publication on emotions. For this introductory analysis, we will mainly focus on her theory as described in *Upheavals of Thought* (2001). However, in the section on fear, we will also draw from one of her applications of her theory of emotions as it relates closely to our project. For this second task, we have chosen her most recent book *The Monarchy of Fear: A philosopher looks at our political crisis*[378] as it shows a concrete example of the application of her theory of emotions as well as being of special interest to our project, as it deals specifically with fear. It also has the advantage of being her most recent publication on the subject of emotions.

Although her 2018 work as well as other recent ventures have enlarged her field of study of emotions in recent years, notably by applying it to politics, her publications on emotions do not depart in a significant way from her first book *Upheavals of Thought*. While some of these books are more concerned with a general audience and her theory of emotions consequently simplified for a larger audience, we cannot accuse Nussbaum of

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[375] She has published over 20 books and hundreds of articles on a large range of subjects, ranging from ancient philosophy to contemporary philosophy, from treatises on subjects as diverse as disability rights to thoughtful aging to works on anger and forgiveness.

[376] Most notably, she has returned to her early conceptualizations of emotions to apply them to society's problems. See for instance: Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York.

[377] We will use her capabilities approach in Chapter 3, at which time we will demarcate her various periods of thought in order to situate the capabilities approach within shifts in her thinking.

[378] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York.

betraying *Upheavals*. Indeed, she often cites this first book as a reference for further reading in order to move forward with her diverse applications of emotions. In turn, this section is not an exhaustive reading of her works on emotions; however, given that there has not been a significant departure in her theory of emotions in later work, we do not see incoherence in relying on these two references to understand both her *theorization* and *application* of her philosophy of emotions.

2.3.3. Nussbaum's Political Project for Philosophy

Nussbaum has not only conceptualized emotions for use in academic discourse. She also has a wider social project that has developed out of her vision of the place for philosophy in public life. While we will discuss in more detail the demarcation of the periods of her thought in Chapter 3, it is worth briefly pausing on Nussbaum's application of her philosophy of emotions to real-life social problems as our method *with* emotions has similar aims. According to Harpham, Nussbaum should not be considered as a philosopher with social concerns, but rather as a social reformer using scholarly methods and materials. Harpham even insists that she is, *"addressing herself not to academic specialists but to human beings."*[379] If we accept Harpham's formulation, this means that the first objective of Nussbaum's philosophy is not to defend philosophical traditions,[380] but to serve as a guide to living. Nussbaum prefaces her 2018 book, *The Monarchy of Fear*, by saying,

> *"Academics can be too detached from human realities to do good work about the texture of human life…my own commitments and efforts have always led me to want to restore to philosophy the wide set of concerns that it had in the days of the Greeks and Romans: concerns with the emotions and the struggle for flourishing lives in troubled times; with love and friendship; with the human life span…with the hope for a just world."*[381]

We can see from this quotation as well various works that her application of her philosophy of emotions is *engaged*, by which we mean that it is looking for real-world solutions. For this task, she uses many kinds of information to convince other philosophers with her ideas, but she also addresses herself to non-specialists. She also does so by using

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[379] Harpham, G.G., 2002. *The Hunger of Martha Nussbaum*. Representations 77, p. 55.
[380] It could be argued that Nussbaum mainly had these priorities early in her career, before work on the capabilities approach, which led her to engage in social reform efforts. See Chapter 3.
[381] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. p. 15.

philosophy — but also other information and other disciplines, including but not limited to novels, laws, and political discourses.…all resources in sum which are "necessary" to speak to human beings. Nussbaum's project is double: to make a social contribution to philosophy through *concept development*, such as she as has done in *Upheavals*, but also to make a social contribution by *the application* of her philosophy to society's problems.

One of the ways in which Nussbaum has engaged a larger public is specifically her work on emotions applied to society's problems. Her 2018 book, *The Monarchy of Fear: A Philosopher's Look at Our Political Crisis*, uses emotions, notably fear, to provide new reflections on the current political crisis in the United States. She freely uses non-academic sources such as experiences of her research assistants, recent laws, and speeches by politicians to argue for her ideas. By so doing, she is making her material relevant, familiar, but also accessible to a non-philosophical audience. In other words, she is addressing herself specifically to her fellow citizens — as a fellow citizen—and asking for a place at the table in these discussions. This book uses the main ideas outlined in *Upheavals*, but she applies them to the current political crisis to offer solutions.[382] Here is a clear example of the application of her theory of emotions to the service of society.

Our research project has a similar aim in that it is destined for use in the field. Working with the actors involved was therefore a necessary part of the research project. Our use of Nussbaum's philosophy of emotions stems from its ability to help us understand and find potential solutions to the problems identified by our patients. Because of this, we have taken the participant's ideas themselves as the source of knowledge (in the spirit of epistemic contribution), and we will show how the rich contextualization of these individual narratives of patients has enabled new themes to emerge.

[382] In the book, she uses emotions such as fear, hope, and disgust to show why various political parties have been unable to hear each other, and she uses again her theory of emotions (especially hope) to show ways to get out of this impasse.

2.3.4. Intelligence of Emotions

Let us now highlight Martha Nussbaum's philosophy of emotions. This section is largely a reading of her ideas from *Upheavals* in order to introduce aspects that will be important for development of the method *with* emotions and for the analysis of these emotions. In the next section, we will present our critique of her ideas and a necessary reformulation for our project, based upon our fieldwork.

For Nussbaum, emotions are part of our system of ethical reasoning because they are, "*intelligent responses to the perception of value.*"[383] She defines emotions as, *"appraisals or value judgments, which ascribe to things and persons outside the person's own control great importance for that person's own flourishing."*[384] She argues that emotions always involve thought of an object combined with the object's salience; thus they always involve appraisal. This is what she calls her *cognitive-evaluative* view.[385] It is not that emotions have a cognitive component more than other elements, but rather that they are themselves cognitions and that these cognitions are necessary and sufficient.[386]

To order to build her theory, first, Nussbaum says that emotions are about something: they have an object.[387] Secondly, this object is *intentional*[388], meaning that it is seen or interpreted by the person who is experiencing it. She claims that their aboutness is internal as it embodies ways of seeing.[389] Therefore, emotions are from the personal perspective and contain a reference to the self.[390] Third, she says, "*emotions embody not simply ways of seeing an object, but beliefs — often very complex — about the object.*"[391] In general, these objects are persons, things, events, that represent an importance for the well-being of the person who is experiencing it.

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[383] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 1
[384] *Ibid*., p. 4
[385] *Ibid*.,. p. 23
[386] *Ibid*.,. p. 34
[387] *Ibid*., p. 27
[388] She goes on in later chapters to distinguish between appetites and emotions by saying that emotions are pulled into being by their object and the importance of that object. Thus intentionality is essential to understanding that emotion. She says that bodily appetites are "pushes" that arise as a result of the body and that causes the appetite to represent an object that it seeks. This has consequences for adaptability: emotions go away when relevant beliefs about the object and the value changes, unlike appetites. *Ibid*., p. 131
[389] *Ibid*., p. 27
[390] *Ibid*., p. 52
[391] *Ibid*., p. 28

Furthermore, she says that emotions are concerned with *value*, in that the object of the emotion has an importance for the person experiencing it.[392] Here Nussbaum connects *value* with *flourishing*, by saying that the object of the emotion will show something of importance about the life of that person. For Nussbaum, *"emotions…insist on the real importance of their object, but they also embody the person's own commitment to the object as part of her scheme of ends."*[393] This means that emotions are not (only) tools or instruments just for the person's own satisfaction, but also that they may be invested with intrinsic worth or value.[394] Thus for Nussbaum, emotions are cognitions that help us evaluate the importance of the object of the emotion to our flourishing. They have value as they are somehow invested in the person's life projects. This idea gives further weight to emotions in our moral lives because they show us things of great importance to ourselves. We will see how relevant fear is to our *eudaimonia* in the next section.

Emotions and Vulnerability

A key idea in which Nussbaum's cognitive-evaluative view of emotions depends is vulnerability. Vulnerability for Nussbaum stems from the idea that human beings are born into a world in which they do not fully control.[395] The recognition that good things and their absence have an external source makes these emotions have salience even before the infant has understood the idea of an external object.[396] However, once when an infant realizes that this need is focused on an external object, she becomes shameful. This is shame of a specific sort: the inability to control the situation, recognition of her own incompleteness.[397] This causes *ambivalence* as the child is still needy, yet recognizes that their neediness has to be fulfilled from an external object. For Nussbaum, our emotions experienced in later life have roots in these early experiences. She says that, *"the roots of anger, hatred, and disgust lie very deep in the structure of human life, in our ambivalent relation to our lack of control over objects and the helplessness of our own bodies."*[398] Objects that we need, but which are largely outside our control, are our *external goods*. They were formed in early childhood, and they continue to exist, and conflict, with the

[392] *Ibid*., p. 30
[393] *Ibid*., p. 33
[394] *Ibid*., p. 31
[395] *Ibid*., p. 181
[396] *Ibid*., p. 193
[397] *Ibid*., p. 196
[398] *Ibid*., p. 234

person in her adult emotional life. We continue to need these external goods that are outside our control, but to have an ambivalent relationship to them (because of our need for them), leading to emotions such as anger, fear, and disgust.

Neo-Stoic View: Emotions as Judgments

To account for these propositions and to go further, Nussbaum proposes a Neo-Stoic reformulation of emotions as *judgments.* She says this judgment has two stages. In the first stage, one thinks that things are that way, or to use her words, it "occurs" or "strikes the person" but the person has not really accepted them as they are. There follows several possibilities, which she calls "judgments" in which one can either accept or embrace these appearances. These judgments transform into "beliefs" about the way things are.[399] Nussbaum specifies that this action (assenting/rejecting/absence of judgment) is an act of cognition. It is therefore a form of reasoning, in which the person assesses the situation and makes a judgment about its importance.

However, she is not saying that these judgments are always voluntary. She says, *"habit, attachments, and the sheer weight of events may frequently extract assent from us; it is not to be imagined as an act that we always deliberately perform."*[400] She says that our emotions and our judgments on these emotions are not fully within our control. In order to do so, she admits considerable place for the external environment in determining/influencing these emotions; however, she largely discounts the body in its environment and in these evaluations. This is our main critique of her theory, which will be highlighted in the next section.

Emotional Intensity

Nussbaum departs from the Stoic view on a number of points. The first is the idea that emotions have to do with whatever a person values, no matter how well or how discordant these values fit together, nor if they are necessarily things that the person commends to others.[401] She also takes objection to the ancient Stoic view that people cherish and value things and persons they do not necessarily think as good, but they do so anyway[402] (due to their family background, their feelings about a particular person, etc.)

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[399] *Ibid*., p. 37
[400] *Ibid*., p. 38
[401] This statement is also a departure from the Aristotelian system of goals. *Ibid*., p. 49
[402] *Ibid*., p. 51

Another critique of the Greek Stoic view is that if this appraisal is related to one's *eudaimonia*, then it is not possible to preserve the emotional equanimity[403] advocated by the Stoics given the importance to the person's important goals and ends.[404]

In making this last claim, she gives particular salience to the *intensity* of the emotion. We can therefore understand that difference of intensity of an emotion can be explained by the *importance* with which the person invests in the object among their own goals and projects.[405] The intensity of an emotion is to be taken seriously, as it shows what is particularly important for the person's *eudaimonia*. Here though she acknowledges that emotions are frequently disproportionate to their object. We often have a skewed view of the object, seeing them more or less important than they really are. Whether or not the evaluation of the object is skewed will be interesting for our project, but regardless this does not change the idea that an emotion is an evaluation of the importance of the object. This idea will be of some importance to understanding our fieldwork.

Emotional Imagination

Nussbaum shows us that emotions are richly particular, and that they are cognitively laden, meaning that they have a connection to imagination that differentiates them from more abstract judgments.[406] This leads her to say that imagining is a way to make a *eudaimonistic* connection with the object. She says,

> *"I won't really succeed in caring about those people as part of my scheme of goals and ends without such rich imagining…here what the imagination seems to do is to help us bring a distant individual into the sphere of our goals and projects, humanizing the person and creating the possibility of attachment.*"[407]

This role for imagination in emotions can help us understand a number of things, such as why our emotions can be disproportionate to their object or why emotions can lead to an erroneous judgment.[408] It can also lead to a number of other reflections such as our

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[403] *Ibid*., p. 40
[404] *Ibid*., p. 41
[405] *Ibid*., p. 55
[406] *Ibid*., p. 65
[407] *Ibid*., p. 65-66
[408] Nussbaum does not claim that the evaluation of the emotion by the person is accurate, merely that it is important for the person concerned. Thus, having emotions depends on what the person's beliefs are, not whether they are true or false. According to Nussbaum, the mind, *"has complex archaeology, and false beliefs, especially about matters of value, are difficult to shake."* Thus, it is perfectly possible that emotions show false beliefs. Whether or not emotions show false beliefs will be an interesting part of our analysis (in

ability to empathize with others or why a particular object/event/relationship is important in our lives. It can also help us explain how our emotions can change: an object of fear, for instance, in one situation can become magnified when we imagine a past event: imagination therefore helps us take on significance not immediately apparent.

General and Particular Emotions

The imaginary in Nussbaum's account of emotions leads her to further distinguish between the general and the particular. Nussbaum gives the example of her grief about her mother: she felt the emotion of grief both due to the particular object (the person) with whom she shared many memories, but also in terms of the generality (she had no parent left).[409] In many cases the general and the particular are simultaneously present; however, this general/particular distinction can affect both the intensity and the salience of the emotion. If the object is general (for instance a need to be loved), rather than tied to a specific person, this could mean that the object of the emotion is replaceable. This generality would therefore suggest that this emotion may be intense in its temporality but will likely disappear with time. If the emotion is tied to someone who is irreplaceable, such as a parent or a child, however, it can take on a particular intensity. This distinction between general and particular will help us to understand the parent's fear toward their child: because the child cannot be fully replaced, the cause of the fear comes from both this general idea of the family as well as the particular salience of their child to them.

Background and Situational Emotions

Another element will be important to help us analyze our fieldwork: Nussbaum's distinction between background and situational emotion-judgments. She distinguishes emotions that arise in particular situations, or those that persist in time (background emotions).[410] Nussbaum largely sees these temporalities in a continuum, as most emotions can be situational yet relatively enduring, and background emotions become situational emotions owing to different situations.[411] This means emotions have a history.[412]

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particular in the doctor-patient relationship); however, what interests us most in the usage of a method *with* emotions, following Nussbaum's philosophy, is not whether or not the emotion is "objective," but rather that the emotion expressed is a judgement for the person concerned. *Ibid*., p. 36

[409] *Ibid*., p. 66

[410] *Ibid*., p. 69

[411] *Ibid*., p. 69

In our discussion, we are also interested in how these emotions impact actions. Identifying actions will help us to unblock these emotions or at least to recognize their importance to the person concerned. For instance, for a situational emotion to occur, it is usually necessary that some kind of background judgment be combined with a specific judgment that puts the emotion's object in a concrete way in some actual, or imagined, context. Background fear of death for instance becomes situational when combined with a specific event in which a person's vulnerability is put into focus.[413] Both types of emotion can guide specific actions, whether or not they are an accurate evaluation of the event.

2.3.5. Toward a Method *with* Emotions

We have here briefly introduced the important elements of Martha Nussbaum's theory of emotions to our project: the integration of vulnerability and lack of control; the possibility for background judgments affecting our actions; how imagination augments or diminishes fear; and the possibility that emotional judgments can be erroneous. The common thread is that it is not only the emotion or the emotional expression by itself that is important, but what it shows us about ourselves, about our values, about our vulnerability. This vision of emotions helps us to evaluate objects, persons, events in the world in relation to ourselves, to our values, to what is important to us to live well. In other words, emotions are tied to our *eudaimonia* and thus must be taken seriously. In addition, we are interested in what emotions can lead to, and how they can be changed. In reference to the philosophical debate on whether or not emotions can be taught, therefore, Nussbaum is making a stand that 1) emotions can be taught; 2) that they are taught very early on in infancy; and 3) that as emotions such as fear, anger, and disgust are taught from these early development stages, then they should be of our particular concern. It is now possible to fully describe the method *with* emotions:

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[412] Here she criticizes the Stoics and the "cognitive account of emotion in philosophy" for omitting the past as a temporal category. *Ibid*., p. 177
[413] *Ibid*., p. 73

Table 5: Toward a Method with Emotions

Components
1. Identification of the key emotions expressed by patients when they discuss their epilepsy (either about themselves and others)
2. Clarifying with patients (through interviews) why they have expressed these emotions, in what context, why, paying attention to what actions have followed these emotions
3. Using alternative methodologies to enable rich contextualization of emotions (such as taking the place of the patient through theater) to enable patient contributions
4. Converging recurring themes across research sites
5. Understanding how and why patients have expressed these emotions; what kinds of actions these emotions have resulted in; if there is a distortion or intensity related to the emotion which may signal its importance to the person concerned. This final stage of the method *with* emotion is to understand these emotions through the perspective of the patient's flourishing in order to understand if these emotions help them to live well, or on the contrary keep them from living well, in today's societies.

2.4. Emotions, the Body, and the Environment

2.4.1. Phenomenological Aspect of Emotions

Nussbaum's cognitive-evaluative view is a powerful and convincing emotional theory that has inspired our fieldwork method. However, we would like to propose several critiques and supplements to her theory, as it will be of some importance to be able to understand the findings of our fieldwork. Our critique to Nussbaum's cognitive-evaluative view encompasses two ideas: in the first place, we propose that emotions experienced bodily help us in the evaluation of the object; and secondly, following Merleau-Ponty, that the emotional experience of the body in its *environment* is important to be able to understand — and therefore assess — that emotion.

Nussbaum's cognitive-evaluative view of emotions dominates her Neo-Stoic view, thereby downplaying the bodily experience of emotion. This is understandable as Nussbaum sought to move away from previous emotional theories that minimized emotions in moral evaluation. However, based on the findings of our fieldwork — most importantly fear in the doctor-patient relationship — her cognitive-evaluative view is not sufficient to be able to make sense of our field research. We will argue here that the *phenomenological* character of emotion is also vital to evaluate the salience of the emotion. In addition, we also need to consider the evaluation of the bodily expression of emotions in the other, such as a patient trying to evaluate the doctor's emotions, which Nussbaum's theory does not fully satisfy.

In the first place, to be fair to Nussbaum, according to *Upheavals of Thought*, she would not necessarily disagree with the above statements. Indeed, she states, *"although I believe that emotions are, like other mental processes, bodily, I also believe… that seeing them as in every case taking place in a living body does not give us reason to reduce their intentional/cognitive components to nonintentional bodily movements."*[414] From this quotation, we can see that Nussbaum is mainly taking issue with the reduction of emotions to "nonintentional bodily movements." We are here not proposing a reduction, but rather an *integration* of the phenomenological perspective into the cognitive-evaluative view.

[414] *Ibid*., p. 25

Nussbaum's critique of the phenomenological basis for emotion is based upon its claim (or rather for feeling theorists' claims) to be a *necessary* condition for that emotion. She argues, *"emotions cause physiological effects: so it is extremely difficult to say which effects are consequences and which are even plausible candidates for being parts of the experience itself."*[415] The statement that she is making here is a bit paradoxical: she is saying that emotions cause bodily changes, yet because of their intertwining with the emotion, it is difficult to assess whether they are simultaneous or *a posteri* to the experience of the emotion. We will see how recent cognitive theories of emotion respond to this claim; however, for now let us state whether or not this statement has an impact on our project should it turn out to be true or false.

What is important to our project is not in what temporality these emotions occur (cognitive then bodily or cognitive-bodily simultaneously), but rather what they may show about the person's *eudaimonia*. If we consider that *eudaimonia* as conceptualized by Aristotle, and in turn by Nussbaum, as a long-term activity, concerned with flourishing during the whole life, then the experience of the emotion will be considered in terms of the person's overall life. What comes first (the cognition or the bodily experience) may tell us something about when and how that emotion is experienced in the body, but the question for us is what the experience of an evaluation means for the flourishing of that person. In turn, even if these emotions are first experienced as only cognitive judgments, the does not mean that their bodily expression *a posteri* will not in turn affect that preliminary judgment, changing it in complex ways (because as Nussbaum says, emotions have a history). In both cases, a bodily evaluation may bring insights into our analysis of that emotion and its salience.

Plasticity and Variability

Let us now examine the other critique from Nussbaum to the phenomenological view. She argues that phenomenological experiences of emotions are not a necessary condition of that emotion as they can vary from individual to individual due to the *plasticity* and the *variability* of people.[416] She says,

> *"Even if we don't like totally nonconscious emotions, we should recognize that there is a great deal of variability in the feeling states people characteristically experience*

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[415] *Ibid*., p. 58
[416] She argues for a "social constructivist view of emotions." *Ibid.* p. 60

> *in connection with a given emotion-type — variability both within a given subject and between subjects. My anger exemplifies both of these points: for at times it is entirely asymptomatic; and then, the following day, it will manifest itself in a headache. In neither case does it have the phenomenology of 'boiling' that so many people report."*[417]

We agree with Nussbaum that a particular phenomenological experience of emotion is not necessarily universal, being highly variable from individual to individual, from culture to culture. What this means, however, is that the environment is another key factor that must be considered in the evaluation of that emotion.

2.4.2. Hybrid Theories of Emotions

In the past few years, emotions theorists have attempted to balance the bodily and cognitive viewpoints into different hybrid theories.[418] Scientific studies have led weight to these hybrid theories, showing us how emotions prepare us to meet the challenges in our environment through adjustments in skeletomuscular, neuroendocrine, and the autonomic nervous systems.[419] What emerges from these debates is that evaluations of these emotions through bodily changes help people to voluntarily change their behavior to meet the challenges of their environments. Until the debate on the *necessary* phenomenological component of emotions is resolved by neuroscience or another discipline, these advances still show us an unavoidable idea: bodily expressions of emotions are tied to their cognitive evaluations and these cognitive evaluations lead to actions of adaptation. Nussbaum's theory is not sufficient to help us to understand how the phenomenological content of these emotions can show us the salience of the object to ourselves, nor how we adapt to these changes, and what this means for the person's flourishing. We will therefore need to take a hybrid view, by keeping the cognitive-evaluative aspect of emotions related to the person's *eudaimonia*, but by allowing that the phenomenological content can have salience in the person's evaluation.

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[417] *Ibid.*, p. 61

[418] Maiese outlines several of these cognitive theories in her article. For our purposes, we will partly use Maiese's hybrid formulation as it aligns with our project. Maiese, M., 2014. *How can emotions be both cognitive and bodily?* Phenomenology and the Cognitive Sciences 13, 513–531.

[419] Nummenmaa, L., Glerean, E., Hari, R., Hietanen, J.K., 2014. *Bodily maps of emotions.* Proceedings of the National Academy of Sciences 111, 646.

Affective Framing

A diversity of propositions has been developed in recent years for different hybrid cognitive-feeling views. We will highlight two that have salience for our project: the affective framing theory of Maiese and the cognitive preconditions identified by Gunther. To start with Maiese, she maintains, like Nussbaum, that emotions have intentionality. However, she proposes that the phenomenal character or affective feel of emotion is inseparable from this intentionality.[420] This means that the body and the intention are closely linked to what the emotion is about.[421] She claims that, "*insofar as emotions count as ways of representing or interpreting objects, emotions are cognitive. But it is also true that emotions essentially involve our bodies in our apprehension and appraisal of our surroundings; thus, emotions are bodily.*"[422] In Maisie's hybrid view, the phenomenal experience of emotion is inextricably linked to its cognitive content. Nussbaum would again not necessarily disagree with this statement; however, by saying that it is impossible to understand under what temporality emotions can occur, she largely dismisses the phenomenological feature to emotions as a necessary condition to the expression of that emotion. Maiese — and we — maintain that the phenomenological character is inseparable from that intentionality: in other words, we cannot have intention without the body. The body helps us see the salience of that object. This means that the phenomenological character of emotions is inseparable from the evaluation of the object.

Maisie also maintains that a different intentionality will correspond to different bodily profiles. She says that bodily feelings help to determine the cognitive focus of emotions, affecting how the brain will determine what is important.[423] Maisie calls this affective framing.[424] As affective framing happens in a complex network of brain and bodily processes, these processes are inevitably intertwined in a bodily way. This idea of affective framing is useful for our project if, following Nussbaum, we say that what is in focus in a bodily and cognitive way is something of importance to our *eudaimonia*. This

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[420] Maiese, M., 2014. *How can emotions be both cognitive and bodily?* Phenomenology and the Cognitive Sciences 13, p. 518.
[421] *Ibid.*, p. 519
[422] *Ibid.*, p. 519.
[423] *Ibid.*, p. 525.
[424] Maisie says that, *"affective framing is best understood as distributed over a complex network of brain and bodily processes; it engages not just the brain, but also metabolic systems, endocrine responses, musculoskeletal changes, and cardiovascular responses. A subject's way of framing is also embodied partly in her facial expressions, gestures, posture, movements, and overall bodily comportment."* She says that if subjects did not rely on affective framing, then they would be faced with a potentially endless variety of choices. Framing thus allows the subject to determine what is most salient to them. *Ibid.*, p. 525-526.

will allow us to say that the bodily experiences of emotion will *also* help us to evaluate the object and its relationship to the subject's flourishing.

Cognitive Preconditions and Bodily Shades

Now let us now look at the contribution of Gunther.[425] He proposes that emotions have intentionality, cognitive preconditions[426], and are felt phenomenologically.[427] Like Maisie, he recognizes the intentional content of the emotion, as well as the indissoluble aspect of both cognitive and bodily aspects to emotions. According to him, *"the intentional content is imbued with the phenomenology and is experienced as an indissoluble aspect of it."*[428] Gunther however adds the idea of cognitive preconditions, which he defines as the idea that, *"emotions presuppose that the individual possesses corresponding belief."*[429] This idea is similar to Nussbaum's idea of background emotion, i.e. those emotions that can come prior to the situational experience of the emotion, as they have been to use, Gunther's words, *cognitively preconditioned*.

Gunther's idea partly explains Nussbaum's temporality problem. If we have cognitive preconditions, that means that the cognitive-evaluative element may come before the bodily experience of that emotion. However, just because an emotion has a precondition or as Nussbaum calls it, a background, that does not mean that it is divorced from the phenomenological content in its conditioning nor that it is separated from the later phenomenological content when it affectively comes into focus. Nussbaum's and Gunther's attempts to understand the temporality of the cognitive and phenomenological experience of an emotion show us the messiness of question: if it is difficult to unravel, it is perhaps because both are so inextricably tied together.

In addition, even if the temporality of an emotion is important, an evaluation of an emotion is not a one-off event: as Nussbaum showed, it has a history, and is linked to an ongoing evaluation of the salience of the object to our flourishing. Whether or not emotions have *necessary* phenomenological content in a specific temporality is therefore not really the issue. What is at stake is our evaluation of that emotion, which is helped

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[425] Gunther, Y.H., 2004. *The Phenomenology and Intentionality of Emotion.* Philosophical Studies: An International Journal for Philosophy in the Analytic Tradition 117, p. 45.
[426] *Ibid*., p. 50.
[427] *Ibid*., p. 43.
[428] *Ibid.*, p. 48.
[429] *Ibid.*, p. 50

along by the cognitive and bodily evaluation of that object, in a one-off but also in a long-term temporality, once those emotions return to the background.

Gunther also proposes that emotions, like colors, have different "shades" which differ depending on the experience of that particular emotion.[430] The idea that emotions have shades gives salience to the intensity when we experience an emotion. While Nussbaum has discussed different intensities of emotions and what this shows about the salience of the emotion in the person's life, she has not taken into account how this affects the differing lived experience of emotions in the body, or how this lived experience in the body might affect the evaluation of the emotion by the person concerned.

2.4.3. Emotions in the Other

We also argue that Nussbaum has not adequately taken into account what it means to live the emotion of another. Witnessing, or rather "seeing/feeling" the bodily experience of emotion of the other is our primary means to experience the emotion of another person. The link between emotions and bodily states is also reflected in the way we speak of these emotions.[431] We cannot have access to the other person's cognition; our main means of assessing the other person's emotion is through their bodily behavior. We effectively see through the body of the other their emotions.

In the case of fear for example, we can witness the widening of pupils, the lack of eye contact, a defensive posture, etc. All of these bodily expressions are signals of fear are for us, the exterior person witnessing the event. While Nussbaum maintains with difficulty that many expressions of emotion are particular to individuals and particular to cultures, she does not sufficiently recognize that we do share some ways of expressing emotions within cultures, but also in our globalized world, particularly for emotions such as fear which have strong phenomenological content shared across cultures. Nussbaum's view does not help us to understand this evaluation of the other's emotions, in that we seek clues to the emotions of the other through their bodies. This is an everyday practical habit, one which we do in an instinctive way: our evaluations of the other depend on bodily movements and we are generally not that bad of a judge of those bodily expressions of our

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[430] Gunther says that, *"some manifestations of anger may be more intense than others, some joy more brilliant, and so on." Ibid.*, p. 46

[431] Nummenmaa, L., Glerean, E., Hari, R., Hietanen, J.K., 2014. *Bodily maps of emotions*. Proceedings of the National Academy of Sciences 111, p. 649.

emotions (as we will see when we examine the doctor's fear). What Nussbaum, however, brings to our subject is that we may make false evaluations because of these individual and cultural variations. Thus, we cannot assume that what we see in these bodily movements is what is true for the person expressing the emotion.

Again, whether this evaluation of fear is right or wrong is of considerable interest; but the main concern to our project is what this evaluation may show about *eudaimonia*. When we examine the place of fear, notably the patient-doctor relationship, what will be important is not only the experience of fear lived by the person (the patient or the doctor), but also the experience of witnessing the bodily manifestation of that fear in the other and our reactions to that fear. If these experiences are cognitions, they are also lived bodily, and their salience also comes from living and seeing the emotion lived bodily in another. Thus, we maintain that bodily experiences have an important place in emotional evaluation, in equal par with cognitions and can show us what is important for the person concerned.

2.4.4. Emotions and the Environment

Taking into account both the emotional and the cognitive aspect of emotions will also permit our patients to be situated bodily in their environment. Recent studies suggest that the cognitions surrounding emotions help persons to adapt to their environment.[432] What is missing from Nussbaum's cognitive-evaluative view is this integration of the body into its world; by consequence it does not give adequate space for the environment in shaping our emotions and evaluations of those emotions. Again to be fair to Nussbaum, she does emphasize the particularity of emotion in relation to its environment[433]: after all she believes, following a social constructivist view, that emotions will be expressed in different ways depending on the person and their environment. This explains how the environment will affect the person's *eudaimonia*; hence the central role of emotions in helping the person determine what is salient. However, she does not give an adequate place for the body in its environment in evaluation of those goals.

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[432] *Ibid*. p. 646.

[433] Nussbaum says that, *"animals need things from their world. They are organized systems living in an environment and adapted to it. They therefore need to attend closely to what is going on in their environment, and to assess it as it bears on their goals."* Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions.* Cambridge University Press, Cambridge ; New York. p. 106

Merleau-Ponty tells us that, *"our natural attitude is not to experience our own feelings or to adhere to our own pleasures, but to live in accordance with the emotional categories of the environment."*[434] This statement is of importance to our project of evaluating fear. Nussbaum has gone part of the way by saying that judgments of emotions are not always voluntary[435]; however, she has not explained how this environment will affect the bodily experience of these emotions, nor has she fully explained how the body in the environment can influence the emotion's evaluation. Therefore we maintain that the bodily expression of that emotion in its environment is also necessary to our understanding of the emotion.

In addition, our case study of epilepsy shows a further difficulty. The lived experienced of the seizure is sometimes not cognitive, if we take into consideration that many epileptic patients lose consciousness during seizures. If the experience of the seizure for the person concerned is bodily, even then the body experiences the seizure *a posteri*, after consciousness has at least partly returned. The evaluation of the event is in the first case bodily (the person "feels" what happens to the body) when they regain consciousness. The emotion in turn felt by the person following this bodily experience however is intimately related to the environment. Where and when, and with whom, the seizure is experienced may solicit the emotion felt *a posteri* by the person who had the seizure. In other words, the environment in which the seizure occurs can cause the person to feel secure or to feel scared. Thus, emotions felt and lived bodily in the patient's environment can be in turn amplified or lessened. Furthermore, this experience in the environment influences both cognitive and bodily learning of these emotions. As we will see with fear, the learned experiences of fear in particular environments lead to evaluations of oneself and amplifications of emotions in same, and dissimilar, situations.

Based upon the elements we have presented, we will support our own hybrid view, by accepting that both the cognitive and the bodily evaluation of emotion have salience to the evaluation of the object of the emotion. We also maintain that the environment and the body *in* the environment remains an important means to understand these emotions and their importance. Let us now turn to the specificity of fear, to understand what this particularly strong emotion may be able to show us about the person's *eudaimonia*.

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[434] Merleau-Ponty, M., 2005. *Phenomenology of perception*. Routledge, London. P. 442

[435] As she says, *"habit, attachments, and the sheer weight of events may frequently extract assent from us; it is not to be imagined as an act that we always deliberately perform."* Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 38

2.5. The Specificity of Fear

Through our fieldwork and our method *with* emotions, we have identified the emotion of *fear* as salient to the patient's capacity to live well. In the next section, we will be investigating the various relationships of fear in the life of the person with epilepsy. However first we will be investigating what Nussbaum has to say about this emotion, but we will also take into account what a hybrid phenomenological-cognitive view will show us about fear. We will also look at what sociologists can bring us to the investigation of this particularly tumultuous emotion.

2.5.1. Nussbaum on Fear

Nussbaum's focus on fear is very recent. While she mentions fear in *Upheavals* and other works that have applied her philosophy of emotions to various social and political problems, it is with her 2018 book, the *Monarchy of Fear* that she came to focus on fear specifically in relation to the other emotions.[436] However, even in this 2018 book, which has fear in its title, she returns to her earlier conceptualizations of the emotions of anger, disgust, and envy to connect them to this new topic. She highlights this fact in her most recent book: "*Having worked for many years on each emotion more or less in isolation from others…I've come to realize…that fear is primary, both genetically and causally, and that it is because of infection by fear that..other emotions…turn toxic.*"[437] We will take interest in one of the connections that she identified in this book: the link between fear and disgust. For now, let us discuss what Nussbaum has to say about fear in line with her overall theory, as despite this (recent) interest specifically in fear, she has developed a number of reflections on fear in *Upheavals*.

Nussbaum says that fear is not only the earliest emotion in human life, it is also one broadly shared by other animals. While other emotions (such as compassion) require sophisticated cognitions, fear only requires the awareness of a possible danger.[438] For

[436] In *Upheavals* she deals with wonder and compassion; other works have notably taken on the role of anger and disgust. See for example: Nussbaum, M.C., 2016. *Anger and forgiveness: resentment, generosity, justice.* Oxford University Press, New York

[437] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. p. 9

[438] In this analysis, she was largely inspired by LeDoux's work that showed that fear has a close connection with the amygdala, which is aroused when animals experience fear. As the amygdala is present in all

Nussbaum, fear remains a necessary precondition for our *eudaimonia*: survival and well-being. Without fear, we would not live long in society: if we were not scared of crossing the street for example, we could soon be hit by a car. Thus if fear is a particularly intense emotion, it is not necessarily a negative emotion, as it helps keeps us alive.

As with other emotions, Nussbaum claims that fear is linked to the helplessness experienced in infancy. She claims that, in the world into which the infant enters, there is, *"one overwhelming emotion* (which has) *a formative influence on daily life…fear."*[439] The infant enters a world with intense and pressing needs, which can only be satisfied by others; the fact that that these needs are supplied by forces uncontrolled by her makes this first period of life filled with fear. Nussbaum says that fear involves the belief that bad events are coming and the person concerned is not entirely in control of being able to mitigate the danger.[440] These early nightmares of early fright stimuli go on to endure throughout our adult lives.[441] According to Nussbaum, during times of intense emotion, such as fear, we return to these early traumatisms, to our early insufficiency and neediness.

Fear of Death

Although fear early on in one's life is related to the infant's pressing "survival needs," as the child develops, another fear enters the picture: the fear of death.[442] Humans are prewired to respond to their need for survival. This fear of death persists throughout our lives, often in the background, but is brought to our attention before events and circumstances that remind us of the fear of oncoming death. If the fear of death was always, to use her terminology, *situational*, we would not be able to have any agency. We would be paralyzed into inaction. Thus, Nussbaum says that this omnipresent fear of death mostly remains in the background, for our survival but also for our social needs. Nussbaum, however, disagrees with Lucretius' claim that the fear of death is the cause of

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vertebrates, it shows us that fear is linked to our evolutionary mechanisms of avoiding danger. According to Nussbaum, LeDoux says that while the amygdala is part of a complex brain network, he does not claim that fear is *in* the amygdala. See: LeDoux, J.E., 1998. *The emotional brain: the mysterious underpinnings of emotional life*, 1st. Touchstone ed. A Touchstone book. Simon & Schuster, New York, NY. *Ibid.*, p. 24-27.

[439] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York., p. 23

[440] *Ibid.*, p. 24

[441] *Ibid.*, p. 19

[442] *Ibid.*, p. 40

all other fears in human life.[443] She says that there are many reasons other than death to fear (due to our human vulnerability and incompleteness).[444]

We agree with this claim, based upon our fieldwork; however, as we will show, this fear of death overhangs the life of the epileptic, leading to a variety of complex strategies for herself and her entourage. Therefore, we maintain that this *fear of death* is omnipresent as a blocking factor in the person's flourishing. Fear of death will therefore remain — unfortunately — an important concept to explore in our analysis. Given its evolutionary heritage, that means it will also be the most difficult to change. However, we do agree that fear is also linked to many other complex social fears. There are fears of showing vulnerability and insufficiency to others, fears of being different, fear of the judgment of others, etc. These fears are at once based upon our evolutionary needs for survival, but also on our need — and desire — to live well in society, despite our different capacities (and capabilities[445]) to do so. We will highlight the contributions of sociology in the next section to better understand these other fears.

Fear as a Destructive Force

From these examples, we can see that fear is not necessarily a negative emotion, as it is linked to our survival. For Nussbaum, however, the problem with fear it is that it is a type of augmented consciousness, highly narrowing. Fear means that the self becomes larger, omnipresent, driving out thoughts of others. It is thus a shortened vision of our bodies and the things connected to this body.[446] Hence the title to her book; she compares fear to a monarchy, caring about nothing and nobody else due to the intensity of this particular emotion.[447] While fear is important for our survival, it can become a destructive force because it has the potential to be exploited by others to other ends. Nussbaum therefore tells us of the dangers of fear. She says that, *"fear has a strong tendency to get ahead of us, propelling us into selfish, heedless, and antisocial actions…more than other emotions, fear needs careful scrutiny and containment if it is not to turn poisonous."*[448]

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[443] *Ibid.*, p. 43
[444] *Ibid.*, p. 43
[445] To make the distinction between capacities and capabilities: capacities include the capacity to do something, whereas capabilities include the socio-cultural environment that Nussbaum calls the "combined capabilities."
[446] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. *Ibid.*, p. 29
[447] *Ibid.*, p. 230
[448] *Ibid.*, p. 5.

Thus, fear is a particularly dangerous emotion. Fear's intensity is particularly detrimental to the person at whom fear is directed. We will see how dangerous fear is to the well-being of our patients, but also to their family and the wider circle of their community. In addition, it can become "chronic" with time: as LeDoux has shown, habituated fright changes the organism, and thus proves very difficult to reverse.[449] We will be exploring the consequences of habituated fear in the next section.

However, in line with our project, we are interested in what the intensity of fear may show us about the importance of the object to the person concerned. Following Nussbaum's philosophy, this means that the object of fear is one that is particularly important (because of its intensity) to the person concerned. We will need to pay attention to fear perhaps more than other emotions present in healthcare and in the patient's daily life. Fear in particular, as a strong and disabling emotion, may give us insight into the factors which block that person's ability to live well with their disease.

One further element must be highlighted before continuing. We must pay head to Nussbaum's warning: fear can lead to false evaluations. Drawing on behavioral economics in *Monarchy*, she maintains that assessment of risk is often inaccurate, as we do not rationally calculate costs and benefits, but rather use a number of heuristics that do not necessarily harmonize with living in today's societies.[450] Fear can lead to false evaluations of danger posed to us through factors in our environment (culture, politics, and rhetoric).[451] Our fears are shaped by these experiences of being in society, and they can lead to destructive ends. The examination of these false evaluations will be of some interest to our project, in particular the false evaluation of the person with the disease in society. Again, following Nussbaum's philosophy of emotions, what is important here is not only the experience of the emotion, but what this false evaluation can lead to: actions that will not necessarily lead to flourishing, or inaction, which could also be harmful (leading to isolation, etc.) for the person concerned.

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[449] Nussbaum adds that, "*once animals are conditioned by a frightening stimulus, they can become unconditioned again only by a very long process of reconditioning. These findings may ultimately help us to explain the tendency of emotional habits and their own recalcitrance to change." Ibid.,* p. 115

[450] Nussbaum in particular says that a common source of fear is the "availability heuristic" or in other words if a problem is particularly vivid, it may overestimate the importance of the problem/danger in reality. This is also a highly narrowing view as it does not allow the person to consider all available options. *Ibid.,* p. 48

[451] *Ibid.,* p. 44

Fear and Other Emotions

Fear and Disgust

An important part of Nussbaum's project in *Monarchy of Fear* is to highlight the link between fear and other emotions, such as disgust, anger, and envy. Indeed as she understands fear as that emotion which can lead to others, it can have a cascade effect. Our goal is not to examine all of these potential linkages; only one connection has been found particularly relevant, *fear* and *disgust*. We will use Nussbaum's link between the two emotions to understand the patient's fear in society, as society's reaction of fear to the person with epilepsy is partly linked to disgust, often leading to stigma and isolation for the person concerned. Thus Nussbaum's link in *Monarchy* remains pertinent for our project.

Fear, Anxiety, Apprehension

Let us also distinguish fear from other emotions or feelings such as apprehension or anxiety. Nussbaum has characterized fear as an intense emotion which has a direct relation to an object. It is an intense emotion that we feel in the presence of a danger or some harm; sometimes this object has a clear relationship to one's survival (such as being afraid of being bitten by a snake), but fears can also take a vague form, such as one's place in society. However, fear is usually directed at some kind of object. Because it has an object, it also usually involves some action to "release the fear" or "get out of danger." Anxiety however usually refers to an unknown or poorly defined threat[452] and thus does not necessarily implicate an action. For Nussbaum, the earliest emotions lived by the infant are likely to be *both* fear and anxiety, as it is a time when the infant comes to realize that some parts of agency are distinguished from the self and thus becomes anxious or fearful about their need for external goods.[453]

Apprehension on the other hand is a vague fear, poorly defined. Apprehension is less intense than anxiety or fear which can be punctuated by intense periods of crisis. We will discuss fear in the doctor-patient relationship, with a rebuttal coming from the field that the fear expressed by doctors is not fear but rather *apprehension*. For certain healthcare providers, the feeling expressed toward our patients was less intense than the

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[452] According to Heidegger, the power of anxiety (*Angst*) comes from its indeterminate nature. The "before one" (*Wovor*) is not specific, as is the case of fear. Corbeil, Y., n.d. *Les deux angoisses d'«Être et Temps» et l'«Unbedeutsamkeit».* Revue Philosophique de Louvain Quatrième série, tome 99, n°1, 2001. p. 29.
[453] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 190.

emotion of fear or even anxiety. We will therefore explore this demarcation and what is might show about the patient's evaluation of that emotion.

The reason we have focused specifically on the emotion of fear in this chapter is a simple one: it is the emotion expressed directly by patients when they discussed their seizures and their lives in society; by their families when they discussed their family member's seizures; and the emotions that come out of discussions around the doctor-patient relationship. Anxiety is however a common problem for patients with epilepsy. A 2017 study in Canada for instance has cited depression and anxiety among the most common psychiatric disorders for patients, especially those with refractory epilepsy.[454] The demarcation between fear, anxiety, and apprehension is one that is not always clear for our patients. This subject is beyond the scope of our research, for the time being, and we will principally focus on fear, as it is the emotion expressed by patients. In addition, when patients discuss fear, it usually has a clear object, which may show us something important about *eudaimonia*. This emotion therefore remains of our particular concern.

Fear and Hope

Before continuing, we will highlight one further aspect of Nussbaum's theory of fear as outlined in *Monarchy*. As we have highlighted, fear is a highly disabling, negative, and destructive emotion, one that persists from our early infancy all throughout our adult lives as we seek to flourish in spite of impending death and difficulties to live in society. However, that does not mean that an emotion like fear cannot be — at least — partially overcome. In *Monarchy*, Nussbaum chooses to end her book on a positive note, by signaling the potential for hope about America's political crisis.[455] Following the Greeks, she defines hope as the flipside of fear. Both involve evaluation of an outcome as important; both involve uncertainty about the outcome; and both involve a measure of passivity or lack of control. However, she says that hope swells outward, whereas fear involves a "shrinking." Hope expands; it can thus motivate us toward action. For Nussbaum, hope is both a practical habit and a choice. If we engage in hope, according to Nussbaum, we can at least partly overcome fear. While we do not exploit Nussbaum's proposed link between fear and hope, we do use a "hopeful" outlook by looking at what

[454] Dworetzky, B.A., 2017. *Worrying More about Anxiety in Patients with Epilepsy*. Epilepsy Currents 17, p. 353–354.
[455] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York.,p. 210

can be practically changed through the emotion of fear. After having described such a desperate situation as the person with epilepsy and her systemic rejection in society, we will be thirsty for potential solutions. While we maintain that fear remains a highly complex and difficult to change, we also think that there is also reason to hope because both individuals and social institutions can go a long way toward assuaging those fears.

Fear: a Simple Emotion?

Nussbaum contradicts herself in her works of *Upheavals* and *Monarchy* on the phenomenological experience of fear.[456] In Upheavals, she makes a "potential" exception to her critique of the social constructivist view of emotions for what she calls some *"simpler emotions, such as fear and surprise."*[457] This allowance is because of the primordial experience of fear. As fear is found in all mammals and is not necessarily connected to an advanced cognition, fear may have a *necessary* phenomenological content. This allowance by Nussbaum shows us that fear is a particularly bodily emotion, even for a philosopher that largely criticizes the phenomenological view.

In contradiction to this earlier admission, however, in *Monarchy*, she restates her social constructivist view of emotions, now including fear into this category, by claiming that the phenomenological experience of fear is not universal.[458] She states, *"fear does involve feelings…but it's hard to define fear in terms of any particular type of feeling. We are on safer ground when we stick to the sort of awareness of objects as good or bad that seems an unavoidably central part of fear."*[459] To reiterate, and as we explore in the limitations of our research, we do not necessarily disagree with Nussbaum's idea that the phenomenological experience of emotion shows high cultural and individual variability; however some common phenomenological characteristics of fear are particularly tenacious across societies. Thus, we will make a concession between her earlier and later viewpoints: some phenomenological aspects of fear may be universal; however, the variability of its expression shows the importance of including the environment into the analysis.

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[456] When she discusses this in Monarchy of Fear, she does not even mention this earlier view. Thus we do not know if she forgot it or just reconsidered her position. *Ibid.*, p. 25

[457] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p.115

[458] She maintains that different people experience fear differently, depending on their history and character; in addition people can have fear without being aware of it. She says that these fears are "non-conscious." Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. p. 25

[459] *Ibid.*, p. 26

Another contradictory aspect between *Upheavals* and *Monarchy* is Nussbaum's characterization in *Upheavals* of fear as a simple emotion. In her later work, she does not call fear a simple emotion; by linking it with other pervasive and complex emotions, its links to our vulnerability from infancy, and the particularly enduring aspect of fear in our lives, she is outlining a complex emotion, difficult to unravel, but of great importance to the person's flourishing. Although she does not state so explicitly, we will suppose that she has modified her view to take into account the learned, complex aspect of fear. Regardless of Nussbaum's perspective, for our project, we will need to envisage fear as a complex emotion, as it involves a complex learning process that it is particularly difficult to change. We will show just how pernicious fear is to the life of the person with epilepsy.

2.5.2. Phenomenological Experiences of Fear

To fully understand our fieldwork, we will need to understand that fear is felt in a bodily way, not only as a cognition linked to awareness of danger. As we have highlighted in the previous section, we maintain that the bodily feeling of fear is important to the evaluation of the emotion and that the bodily expression of fear is tied to its appraisal of importance for the person concerned in her environment. These various bodily changes and associated feelings are raveled up in appraisal of the object of that fear. Endorsing her own hybrid view, for instance, Maisie says,

> *"For it to be a genuine instance of fear, the subject must display the appropriate sort of bodily sensitivity and bodily feelings, and also appraises her surroundings in an appropriate way. What is crucial is the subject appraising her surroundings in a way that we would call 'fear' is partially constituted by her ongoing various bodily changes and associated feelings; and these bodily feelings, in turn, are partly a matter of her appraising her surroundings in a particular way."*[460]

Massie goes further in the importance of the bodily evaluation of fear by showing that making a judgment on the ridiculousness of fear will not necessarily change the bodily experience.[461] This means that fear may supersede any evaluative judgment on the part of the person. The incapacity to change one's bodily states, even when the cognitive judgment on the object of the fear is no longer seen as dangerous, shows the importance of the salience of the bodily expression to our evaluation.

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[460] Maiese, M., 2014. *How can emotions be both cognitive and bodily?* Phenomenology and the Cognitive Sciences 13, p. 54
[461] *Ibid.*, p. 49

While our phenomenological experience of the object may be different from our cognitive evaluation of it (such as our fear of spiders), this does not take away its salience to us (we are scared of spiders and thus we move away from them). Thus, the phenomenological experience may take hold over the cognitive evaluation of that fear and motivate our actions. Nussbaum might want to use this information to argue that it does not have necessary phenomenological content, as it is not directly in harmony with its cognition-evaluation; however, we argue that this information suggests a multiplicity of evaluations (cognitive, bodily, etc.) which are inextricably tied together. If we take seriously the phenomenological content of fear, this means giving a place for bodily evaluation into the person's conception of *eudaimonia*, as well as the actions resulting from that evaluation. Thus with Nussbaum, we can maintain that the bodily experience of fear is perhaps a bad evaluation of the situation concerned in some cases, but we disagree with her that it cannot in turn help the person evaluate the situation, and importantly, help the body adapt to her environment. To repeat, the bodily experience is connected with the evaluation of *eudaimonia* and gives us clues of its importance for the person concerned.

2.5.3. Fear in an Uncertain Age: The Input of Sociology

Before moving forward with our discussion, it will be interesting to highlight the contributions of sociology to this discussion of fear in today's "fluid/liquid" world,[462] notably with the insights of Zygmunt Bauman.[463] Nussbaum has discussed how emotions can be linked to uncertainty, by returning it their source in infancy, showing the uncertainty in which the infant has to come to terms with both helplessness and the need to be nourished from external goods. She says the source of our emotions at least partly explains our ambivalence toward others in our lives. Bauman however will help us to understand the formulation of this ambivalence and its link to fear in the present time. He says that paradoxically in today's *liquid modernity*, where there is an overvaluation of individual liberty, persons must live with increased fragility and vulnerability.[464] In these societies, the responsibility rests on the individual's shoulders: he must perform, he must "sink or swim" or "publish or perish"; in a situation in which "the training wheels are off," and "there is no safety net."[465]

Bauman claims that in this environment there are new experiences of fear. As the responsibility for failure has now fallen on the individual's shoulders, in this new world, we are transiting from "official" to "do-it-yourself fear":

> *"Fear of being branded non-conforming, officially cultivated in the society of discipline, has been in the society of performance replaced by fear of inadequacy. All in all, officially 'emancipated' individuals find themselves not up to the demands of the thoroughly individualized life. The spectre hanging over a society of would-be performers by-decree is the horror of finding oneself deficient — inept and inefficacious; as well as its immediate effects — loss of self-esteem and its perspective sequels — outcast and seclusion."*[466]

In the world of "do-it-yourself fear," you have no one to blame but yourself. You not only live in a performance society, in which considerable uncertainty and change

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[462] Term coined by Bauman. In the book itself, Bauman often uses concurrently the terms "liquid" and "fluid" to make the distinction between the periods of light/heavy capitalism that were relatively "solid" in time, place, communities, and relationships. See: Bauman, Z., 2000. *Liquid modernity*. Polity Press ; Blackwell, Cambridge, UK : Malden, MA.

[463] Bauman, like Nussbaum, has had a prolific career with numerous publications. We have chosen our reading to four of his later works (3 books and 1 article), in which he introduced the concept of "liquid modernity." An important element in the chosen works is developing the link between uncertainty and fear in today's liquid modernity.

[464] Bauman, Z., 2007. *Le présent liquide: peurs sociales et obsession sécuritaire*. Seuil, Paris. p. 78-79.

[465] Common expressions used in English in today's performance societies.

[466] Bauman, W. 2017. *"Afterward."* In Bordoni, C., 2017. *State of fear in a liquid world*, 1 Edition. ed. Routledge, Taylor & Francis Group, London ; New York. Bordoni, C., 2016. p. 113

prevail, but you are also fully responsible for this failure to perform.[467] Bauman says that today, society expects the individual to manage these risks as individuals. However, this responsibility is also bodily: to control their individual bodies, including as a social individual in public spaces. Nussbaum says that this fear of inadequacy has been present from infancy, in a dark place where the infant does not control his basic needs. However, in the performance societies in which we live, fear is also fed by individual expectations.

With Bauman, we can more fully understand the evolving ideas surrounding patient empowerment: the idea of autonomy so promoted in patient empowerment literature has become not a choice, but an obligation. Even more, society's fear and the individual's fear surrounding the disease becomes the problem of the patient to deal with individually, rather than seeing what we as a society can do to support the person. Bauman says ironically, *"there is a nasty fly of impotence in the tasty ointment of freedom cooked in the cauldron of individualization; that impotence is felt to be all the more odious, discomfiting and upsetting, in view of the empowerment that freedom was expected to deliver."*[468] While individuals in today's societies have rights *de jure*, they effectively cannot exercise these rights *defacto*.[469] In other words, we are claiming that patients have choices (all the while putting responsibility on them), rather than recognizing the environment and relationships that make their well-being possible.

Fear and Marginalization

The sociologist Bordoni, building on Bauman's work in *Liquid Modernity*, provides a supplement to this analysis of fear through Freud's conception of *uncanny*. He says that it is not that which is unfamiliar (*unheimlich*) which causes fear, but that which is vaguely familiar.[470] We fear the "other" who is different from us, because it shows us something essential about ourselves. Bordoni also adds the repercussions of acting on this fear. He says that individuals may react in a defensive fashion to the person representing that threat[471] with restrictions on relationships with these persons. Here we see again the destructive nature of fear, its tendency to block or destruct everything in its path, both for the person experiencing that fear and for the person projecting that fear, but also by ripple,

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[467] *Ibid*., p. 113
[468] *Ibid*., p. 35
[469] Bauman, Z., 2000. *Liquid modernity*. Polity Press ; Blackwell, Cambridge, UK : Malden, MA. p. 32.
[470] Bordoni, C., 2017. *State of fear in a liquid world*, 1 Edition. ed. Routledge, Taylor & Francis Group, London ; New York. Bordoni, C., 2016. p. 49
[471] *Ibid*., p. 50

impacting society in a diversity of ways. Bordoni says that while this social fear leading to exclusion is no longer acceptable (by official channels such as law), personal fear on the contrary has become endemic. Personal fear leads to marginalization.[472] Marginalization is individual, imposed by an individual or group, and if we take into account Bauman's view, almost completely the responsibility of the individual person. Currently there is little that the state can do to intervene on this individual marginalization.

From these sociologists, we find a number of ideas which will be interesting to our analysis: fear resulting from not living up to society's expectations of performance; a link between Nussbaum's proposal of fear of inadequacy in early infancy and our inadequacy later in life in order to fit into today's societies; as well as the root of marginalization, due to our "uncanny" realization that one day, we might become one of the non-performers. However, it shows us a worrying trend that we will have to grapple with: if exclusion is no longer on the cards, marginalization is alive and well.

All of these factors will help us to understand the place of persons with epilepsy in their environment, and their ability or dis-ability to be able to flourish in today's societies. The philosophy of emotions of Martha Nussbaum, our hybrid cognitive-phenomenological view, as well as the input of the "liquid society" sociologists give us considerable insight into the analysis of fear to the person's flourishing. We will be able to draw on these insights in order to show what this particularly tumultuous emotion shows us about the patient's capability to flourish with disease.

[472] *Ibid.,* p. 52

2.6. Relationships of Fear in Epilepsy

Let us now move to the heart of our topic. Through the research method *with* emotions, we have identified four key relationships of fear in the life of the person with epilepsy. These expressions of fear involve key relationships important to the patient's life: the relationship to oneself, the relationship of the person in society, the relationship in the family, and the doctor-patient relationship. It is not to be presumed that these manifestations of fear are fully alike. However, several convergences among these fears became apparent during the research period. These convergences include fear of death, following what Nussbaum and other philosophers have long maintained about the fear of death being a prominent feature of our lives, but also fear of inadequacy, as Bauman and other sociologists have identified in today's liquid modernity societies. The fear of the body is also an important factor for the person experiencing the disease as well as for the person who "sees" the body during a seizure. The table below summarizes these convergences:

Table 6: Fear Convergences in Life with Epilepsy

	Fear of death	Fear of inadequacy	Fear of body	Actions of fear
Patient	X	X	X	Isolation; self-induced stigma
Society	X	X	X	Disgust; stigma
Family	X	X		Overprotection
Doctor	X	X		Misdiagnosis; inadequate treatment plans

When highlighting these convergences, we are not presuming that these fears have exactly the same meaning and impact on individual lives. Indeed, as shown in the table above, fear in these key relationships — even if from similar origins—leads to a multitude of actions[473] and reactions: isolation from society; disgust and stigma; overprotection; and medical errors and misdiagnosis. In addition, what is important to our project, following Martha Nussbaum's philosophy of emotions, is the relationship of these emotions — and corresponding actions — to the person's flourishing.

[473] Following Aristotle, we maintain that emotions like fear can lead to practical actions (unlike other "non-practical" emotions such as shame). Fortenbaugh, W.W., 2002. *Aristotle on emotion: a contribution to philosophical psychology, rhetoric, poetics, politics, and ethics*, 2nd ed. ed. Duckworth, London. p.82-83.

We maintain that fear will enable us identify what is keeping the person with epilepsy (PWE)[474] from living well. Indeed the very intensity of fear suggests that we need to analyze it. However, a word of caution is necessary. As Bauman has highlighted, when ideal social arrangements do not become a reality, we have a tendency to suppose there is a lack of good will on the part of others,[475] or in other words, that these relationships of fear are due to "bad guys" that must be reprimanded. While we highlight relationships of suffering for the patient, we are not on the look-out for the "bad guy." Indeed, as we will see, our fears touch on basic human fears, which stem from of our own vulnerability, our lack of control, and our need to live in society. Condemning others would mean condemning ourselves. What we are interested in therefore is not to blame a particular person, but rather to find solutions to mitigate these fears, which cause suffering not only for the person with epilepsy, but also for the persons in society who interact with these persons. In other words, we are not just seeking for the person with epilepsy to live well in society, but for others, too. As Jonas Hans has highlighted in his heuristics of fear, what fear should inspire us to do is a "courage to take responsibility" for these fears.[476]

This section therefore aims to investigate why this fear is expressed, in particular its intensity, and what importance this fear has for both the person witnessing this fear and for the person experiencing it. By seeing these emotions not as irrational feelings, but ones that demonstrate great importance to the persons concerned, we will be better able to understand why and how they fit into the person's life projects. Furthermore, understanding these fears also means taking seriously those fears which are an erroneous evaluation of the situation at hand, because they are also evaluations and are important to the person experiencing them.

Once we are able to understand how these fears are an expression of something important, this will lead us toward some potential solutions to unblock or at least mitigate this fear, both for the object of that fear (usually the epileptic person) and for the person experiencing that fear (usually the witness). Once we establish ways to unblock fear from the person's life, we will be ready to develop the patient's view on empowerment.

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[474] PWE is a common designation in international literature to refer to the person with epilepsy, in order to avoid using the term "epileptic" which carries negative connotations, such as in the "epileptic personality."
[475] Bauman, Z., 2007. *Le présent liquide: peurs sociales et obsession sécuritaire*. Seuil, Paris. P. 77
[476] Jonas, H., Greisch, J., 1991. *Le principe responsabilité: une éthique pour la civilisation technologique*, Passages. Éd. du Cerf, Paris. p. 300

2.6.1. The Patient's Fear

"For when one of his flatterers, named Damocles, dilated in conversation upon his troops, his resources, the splendors of his despotism, the magnitude of his treasures, the stateliness of his palaces, and said that no one had ever been happier:

'Would you then, Damocles,' said he, 'as this life of mine seems to you so delightful, like to have a taste of it yourself and make trial of my good fortune?'

On his admitting his desire to do so Dionysius had him seated on a couch of gold covered with beautiful woven tapestries embroidered with magnificent designs, and had several sideboards set out with richly chased gold and silver plate. Next a table was brought and chosen boys of rare beauty were ordered to take their places and wait upon him with eyes fixed attentively upon his motions. There were perfumes, garlands; incense was burnt; the tables were loaded with the choicest banquet: Damocles thought himself a lucky man.

In the midst of all this display, Dionysius had a gleaming sword, attached to a horse-hair, let down from the ceiling in such a way that it hung over the neck of this happy man. And so he had no eye either for those beautiful attendants, or the richly-wrought plate, nor did he reach out his hand to the table; presently the garlands slipped from their place of their own accord; at length he besought the tyrant to let him go, as by now he was sure he had no wish to be happy.

Dionysius seems (does he not?) to have avowed plainly that there was no happiness for the man who was perpetually menaced by some alarm. Moreover it was not even open to him to retrace his steps to the path of justice, to restore to his fellow citizens their freedom and their rights; for with the inconsiderateness of youth he had entangled himself in such errors and been guilty of such acts as made it impossible for him to be safe if he once began to be sane."[477]

Persons with epilepsy (PWE) often describe living with epilepsy as "living with a sword of Damocles" above their heads. Their lives are lives of considerable uncertainty: when will a seizure occur? Who will they be with? How will others react to their seizures? What will others do to them while they are seizing? What might their body do that could hurt others and themselves? The seizure can happen at any time, and in any circumstance, and in front of anyone: their employers, their mother, their girlfriend, their friends, or in front of strangers. It can happen in the supermarket, at a party, at a job interview. This knowledge of moments of a lack of control of the body causes considerable fear. This fear

[477] Cicero, M.T., King, J.E., 2007. *Cicero: in twenty-eight volumes*. 18: Tusculan disputations, Nachdr. ed, The Loeb classical library. Havard Univ. Press, Cambidge, Mass.

eats little by little at the life of these patients.[478] Life with epilepsy is a constant negotiation with fear, fear of seizures past and seizures to come.

1. Fear of the Body

Elodie's story: *Although she cannot see herself, others tell Elodie that her seizures are "impressive": she has violent tonic-clonic convulsions, in which she yells loudly and clenches her entire body. During this time, she remains conscious. The only way to communicate with her family seems to be yelling, as she cannot control anything else during the seizure. Her family tells her, "calm down, Elodie." But she can only respond by screaming. The impossibility to calm down, to control her body, causes her great anxiety. She describes being in a seizure as being in a horror film.*[479]

Chen's story: ***A****lthough she has finally stabilized her epilepsy, allowing seizures to disappear from her daily life, Chen has decided that she will never have kids. Although it is improbable that her epilepsy is genetic, she does not want to take the risk of passing down her epilepsy to her children.*[480]

Melanie's story : *Usually Melanie's parents know how to take her of her seizures. However one time her parents became really scared. She lost consciousness, and at one point, she stopped breathing. Her parents called an ambulance. When she returned to consciousness, she found herself at the hospital. She was disorientated. She kept going out into the hallway, coming back into her room, completely lost. She kept asking herself where were her parents, where was her house. No one came to see her during this time. She kept thinking that she was going to have a seizure and no one would even notice.*[481]

Three stories of women with a terrible disease called epilepsy: a disease in which the body loses control, in which they find themselves in situations of considerable dependence on others. All of these women are scared of their epilepsy for a common reason: *lack of control* of their bodies. This lack of control represents a risk for themselves, but also a risk for others. For Elodie, who experiences her seizures with consciousness but without control of her body, she lives her seizures like a horror film. This situation is "horrific" because she has completely lost control of her body. For Melanie, who loses consciousness, seizures mean losing control of her body in both time and space. Her fear is from the lack of control of her body in its environment, in its time and space continuum. For Chen, her fear is a lack of control of the body in a genetic imaginary: her inability to

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[478] Our research concurs with empirical research that shows a link between fear and anxiety in epilepsy due to neurological, pharmaceutical, and psychosocial factors. See: Vazquez, B., Devinsky, O., 2003. *Epilepsy and anxiety.* Epilepsy & Behavior 4, 20–25.
[479] Interview conducted at the Teppe in May 2018.
[480] Interview conducted in Shanghai, China in June 2018.
[481] Interview conducted at the Teppe in March 2018.

control what she will pass on to her future children.[482] Even though her epilepsy is stabilized, fear still pervades her daily life and prevents her from planning a family life.

In these three stories, the *fear of the body* plays an intimate part of the expression of their fears. Our body allows us access to the world and to others. Yet for the person who experiences a seizure whether or not she loses consciousness, there is a disconnect between the body and the world. The body becomes the "other," the object of fear both for the person experiencing the seizure and for the person witnessing the seizure. During a seizure, the body becomes not a mediation between the object and the world, but a representation of oneself as another. For the person who does not completely lose consciousness during the seizure, this body disconnect is often described as horrific or even painful.[483]

The person experiencing the seizure finds herself — either in the temporality of the seizure or after it — in a loss of contact with the world and the persons in that world. The person having a seizure cannot adjust to the environment; instead, the environment must adjust to her, or if not, it will be at her and the other's peril. The patient's fear is to be taken seriously: it expresses a rational fear of risk to oneself and to others due to lack of control of the body in its environment. It is a valuable assessment of the person's body in its environment; as Nussbaum reminds us, it is a cognitive evaluation of something of importance to the person concerned. Here we could simply stop and say that this is a fear of death or bodily injury given considerable risk to the person[484], and we will investigate this fear in the next section, but we believe it shows something more interesting to *eudaimonia* than this biological reality.

In Melanie's story, she woke up in an emergency room in which she knew no one, in which she did not recognize the furniture or the room itself. Her fear in this situation did not come from having a seizure, but rather from this sense of disorientation — of not belonging — to this new environment. When a seizure happens, the relationship between the things and persons in one's environment becomes an *alien* relationship, one in which the person can no longer mitigate her agency in that environment. As PWE often describe

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[482] For Aujoulat et al., a feeling of powerlessness (or what could be called "unempowerment") comes from a loss of control in the context of transgenerational transmissions. See: Aujoulat, I., Luminet, O., Deccache, A., 2007. *The Perspective of Patients on Their Experience of Powerlessness*. Qual Health Res 17, p. 778.

[483] One person I interviewed described the pain experienced during seizures as "being run over by a steamroller." Interview at the Teppe, March 2018.

[484] Risks include bodily harm (such as hitting sharp objects while in a seizure), or the body itself doing damage to itself (biting one's tongue, etc.). However, there is also considerable risk for others: this includes activities which may put others at risk, such as driving.

having seizures as a loss of oneself, returning to the body restores the capacity for strive toward one's life projects.

This observation is of some importance to our overall project: after all, we are seeking a certain capacity to act for the patient. The capacity to act in the environment is that essential mitigating relationship that determines all the others. If we extend this to the overall life, not only to a short period of time when the disease appears through the seizure, then this means that the capacity to act is the capacity to act in one's overall life. This means that we need to have a more holistic view of the person with disease, as one in her overall environment. This leads us to solicit patient *life* empowerment, rather than a more reduced version of patient empowerment in the doctor-patient relationship.

The Role of Others

This loss of control places considerable responsibility on others, as seizures represent the borderline of this capacity for agency: the person losing control of her body in her environment lacks agency. It is at this moment that the person is in the most need of external goods. However, Nussbaum, following Seligman, shows that an animal cannot flourish unless it believes itself in its own control and mastery.[485] For the PWE, the seizure is the point that the body becomes not "mine" but another's: the environment — and the persons in the environment — effectively become responsible for that body, as the person is not in control. This, of course, shows that the person experiencing the seizure can in no way be empowered during a seizure; however, we will have to consider what not having control of the body in certain unpredictable moments can mean for the rest of their lives.

This first manifestation of fear in the life of the PWE is perhaps too evident: it is a *necessary* condition in order to flourish to be able to control one's body and one's space in the environment. However, as some people can never fully stop seizures, we cannot expect them to be able to control their bodies in all temporalities or spaces. To accept the PWE as capable of flourishing, we will have to accept a more flexible, fluid concept of control as one in which both the person can have certain flashes of un-control. This means finding ways to ensure that these horrific moments will not affect the person's capacity to flourish. In order to do so, both the person having the seizure, as well as the person bringing assistance, will need to accept the person's vulnerability and their need for external goods.

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[485] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 137

As we will see in the next sections, this acceptation is far from evident, either for the person concerned or for society. It also raises a number of questions: what does a disease in which one loses periodically the capacity to flourish mean to our relationship to our bodies? And what will the fear of loss of control of the body means for life "around" and "between" seizures?

Fear of the Loss of Control of the Body and Helplessness

Let us further understand the lack of control of the body — and ensuing fears — by returning to Nussbaum's philosophy of emotions as linked to development psychology. Nussbaum through inspiration from Freud reminds us that birth means coming into a world of objects.[486] Our first relationships are ones of helplessness and the need for the assistance of others in order to survive. For Nussbaum,

> "*The prolonged helplessness of the human infant marks its history; and the early drama of its infancy is the drama of helplessness before a world of objects — a world containing threatening things and good things, the things that it wants and needs…its relationship to them focuses, from the first, on its passionate wish to secure what the world of nature does not supply by itself — comfort, nourishment, protection.*"[487]

When the infant starts to recognize the clear boundaries of the self and the other[488], when they are traced to a definite agency and when that agency is to some extent distinguished from the self, the emotions will be provided with an object. However, once emotions are linked to some external object, this makes the relationship to others one of *ambivalence*. In turn, this ambivalence to these external goods will continue throughout one's life: we continue, like the infant, to have a fundamental need for these external goods throughout and at various times in our lives, but we also wish that we did not have to rely on others for their provision. Our ambivalence comes from the fact that their provision is uncertain, leading to fear, anger, and frustration when they are not provided.

Once we can survive at least partly on our own, these pressing, urgent needs largely fade into the background. However, disease is one of those life moments when our need for external goods refocuses our attention on our early ambivalence. When disease strikes

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[486] Nussbaum citing Freud's *Group Psychology and the Analysis of the Ego* (1921). He said this is, *"the step from an absolutely self-sufficient narcissism to the perception of a changing external world and the beginning of the discovery of objects."* Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 181
[487] *Ibid.*, p. 182
[488] *Ibid.*, p. 190

— in the case of epilepsy, periodically, without warning — this means returning to helplessness and our evident need for these external goods. Epilepsy is a situational disease that brings into focus these needs, the helplessness of the body in the environment and the need of others to help the person to avoid risk to themselves and to others. Although there may be little to be done during a seizure, there is always the possibility of avoiding risk, of putting the person with epilepsy in safety.

Yet this puts considerable responsibility on others: on the family, on colleagues, on friends, and on strangers, whose actions the person cannot predict. How can the person with epilepsy not be scared of the unpredictability of his body in these situations, given that she is helpless in her environment during the seizure? If the person with epilepsy cannot reasonably predict what others will do, she will reasonably fear the coming of seizures as the "sword of Damocles": the need for others is great, yet the uncertainty of their assistance even greater. The sword represents the imagery of the seizure, the unpredictability of its impact on the person who is afflicted, but the sword is also the environment, and the dangers lurking in that environment in the form of objects (persons and things) which may hurt them when the seizure strikes. PWE that cannot trust in their environment live in considerable fear of what will happen when they lose control of their bodies. Thus, this fear of the body is not only about the borders surrounding oneself; it also is inextricably tied to our relationships with others through the mediation of our bodies.

It can now be argued that PWE reasonably fear these moments of lack of control, but that these moments are only short episodes in the person's life. Even more, we could argue that it is possible to mitigate against the dangers in their environment. In patient empowerment terms, this means that patients must "know" their disease by avoiding seizures as much as possible (limiting stress, doing sports, taking the medication as prescribed, etc.) and engaging in "self-management" strategies to control their body in their environment, such as avoiding risks such as driving, certain professions and certain sports. While all of these strategies may ease the person's fear, this brings up another question: at what point is the mitigation of risk greater than the importance of flourishing, and to whom? Should the person abstain from a certain activity because it represents a risk to others, even if they consider it important to their flourishing? In addition, what is the threshold of necessary risk to enable the person to continue flourishing? This is the dilemma faced in everyday decisions for the person and their family, and it shows us that because risk is a risk for others, not just oneself, the answer to these questions for the PWE becomes situated in their environment.

The risk of losing control of the body in the person's environment is everywhere. Every environment is a risk, and therefore a source of potential fear. As fear is a blocking emotion, one that is highly narrowing, it often encourages hiding or avoidance. It can therefore lead to other actions not at all representative of the risk at hand, to complicated and new representations of fear, inaccurate or accurate, which can stop the person from leading an active life. In other words, the fear of a loss of control of the body has considerable consequences for life around and between seizures. We must therefore look for possible solutions to help the person with epilepsy gain control.

Acceptation of Epilepsy: A Bodily Process

Discourse around patient empowerment focuses on the strategies needed for the patient to live well with a chronic disease. An important factor in order to move from a passive to an active state in these discussions includes disease acceptance. Disease acceptance is expected to involve concrete actions: taking medication, avoiding risks, finding ways to flourish with and in spite of disease. However, what acceptance means for patients has not been adequately explored. Based upon our research, we propose that acceptance be understood not only as a psychological process, but also a dynamic and bodily one that is intimately linked to the environment. We have made a list of the different types of acceptance that patients themselves have identified themselves as important.[489] They include:

1) accepting the diagnosis of epilepsy
2) accepting the inability to be "cured" of their chronic disease
3) acceptance of the continued presence — and unpredictability—of seizures
4) acceptance of dangers to oneself and others because of lack of control
5) acceptance of restricted capacities for work, study, leisure due to the effects of the disease and the treatment

All of these complicated, interlacing factors identified by these patients make acceptation not only dynamic, but also discontinuous, presenting blockages in different temporalities. For instance, acceptance of the risks to others (4) may become blocking when the person wishes to learn to drive; in turn the restricted capacities for work (5) become evident when the person tries to integrate a new work environment. Acceptance

[489] Based upon interviews and ethnography conducted at the medical-social center of the Teppe, March – May, 2018.

includes the environment, and the persons in that environment. Thus acceptance is not an end point but rather a continuum based upon how the person seeks to flourish.

In turn, some patients are able to integrate all of these factors, while others are able to only accept certain aspects. One patient expressed this as, *"well, I accepted to be diagnosed epileptic! But I have to admit it's a real battle to try to cure this disease."*[490] Even though stabilized for several years, she says that epilepsy is not behind her and that "*it's not easy to forget."* While she was able to accept the disease (1), she still could not accept the long-term aspect of keeping the disease (2). As she is waiting to be completely stabilized or even cured of her epilepsy in order to plan her life, not being able to accept all of these elements has so far prevented her from flourishing. Also, if acceptance of chronic disease is a discontinuous process, it is also one with contractions: as this patient said, it was possible to accept having the disease and to be able to move forward in spite of the disease, but not to accept it as final, which prevented her from making "final plans."

The Patient Activation Measure (PAM©) described in Chapter 1 helped us to see activation in its temporality. It suggested that having the knowledge, capacity, and confidence to put into place knowledge and behaviors was dynamic. However, it does not address acceptance in this temporality and the possible effect this could have in patients' ability to have the capacity to manage their illness. If chronic disease and in particular epilepsy is dynamic, and changes with time, so too does acceptance and the influence of this acceptance on the willingness and ability for patients to participate in their healthcare.

Localization of Disease and Acceptance

For the patient with epilepsy, due to the considerable fear of losing control of their bodies, acceptance is also tied to the body. By this we mean accepting the disease includes accepting it as "in" one's body, rather than due to some outside force. However, this bodily acceptance is slightly different from other diseases. In the case of both chronic and infectious disease, various bodily representations may cause fear: for the person with cancer, the imagery of a malignant tumor, bone, tissue; for the multiple sclerosis patient, one of a damaged myelin sheath; for the person with Lyme, a propagating bacteria…while epilepsy also has an imagined location (a lesion in the brain), added on this is a periodic bodily "locus of uncontrol" in other parts of the body and the parts of the body affected by the seizure. These involuntary movements can be vocal (screaming, talking), liquid

[490] Interview conducted at the medical-social center of the Teppe, May 2018.

(involving bodily secretions), and involve various limbs or even the whole body (spasms or other involuntary bodily movements), and will be witnessed by the patient after the seizure in the form of cuts, bruises, scars or holes. As Ray Bradbury says in his novel, *Electricity*,

> *"If epilepsy does have a face, it looks something like mine: a bit lopsided, scars on the eyebrow and forehead and chin. Leftovers of bruises and black eyes. Inside the mouth: scars and holes where chunks have been bitten out. Teeth missing, gums cut. And the eye: that buzz. That fire hiding just behind the eyes – it's like a telephone ringing, waiting for someone to pick it up. That person, that thing I never get to see…"*[491]

Although PWE visualize the disease as located in the brain with imaginary such as "being on fire" or "electrified," there is also an added uncertainty of the body and what other body parts will be mobilized and "shown" to others during or after the seizure. Accepting the disease in a bodily way is therefore an acceptance of uncertainty in the entire body, not just as localization in the brain. It is also an acceptance of "showing" these moments of non-control – and sequelea of this lack of control - of their bodies to others.

Another specificity of epilepsy is its temporality. Acceptance of bodily derailment is acceptance of a disease expressed at unpredictable moments, rather than as a continuum. Although PWE are expected to accept that they have a chronic disease, most of the time this disease is invisible except during a seizure.[492] Even more, as many patients lose consciousness during seizures, they often have no access to these bodily derailments. Not being able to see the seizure makes it hard to accept; accepting to take long-term, heavy medication is a question of trusting others' testimony about the disease and its severity. Thus acceptance of the disease is also a question of trust of the epistemic authority of others such as doctors and the family. Thus once again we see that the patient is not an autonomous individual, as even bodily acceptance of disease is tied to others.

To return to embodiment, while several patients interviewed in this research project described acceptance among the five factors identified above, they also located epilepsy "in" the body as a way to gain control of the disease. Michel, for instance, says that he started to live better once he accepted that the disease was "in him." He described it as, *"before, I was very angry about my disease, but little by little, I understood that the disease was in me…so I had to learn about it…therefore I was much less angry."*[493] Understanding that the disease was "internal," "in himself" and therefore "in his body" let

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[491] Robinson, R., 2014. *Electricity*, Picador. p. 239.
[492] This influences their ideas on being healthy, as we will see in Chapter 3.
[493] Patient interviewed at the Teppe, April 2018.

him appropriate and learn his disease. It was at this stage that he also began to plan his future. Martin has clearly identified for us the link between this bodily acceptance and his capacity to flourish. Other patients have even said that they were able to reduce their seizures once they accepted that the disease was "in them." Thus, we propose that for PWE, acceptance of the disease *in* the body can help to reduce fear. This is our first proposal to help the PWE reduce the fear keeping them from living well with their disease.

2. Fear of Death

Following Nussbaum's philosophy, we have supported the idea that fear is a judgment on the object of the emotion and its importance to our lives. Fear of death shows us something obviously important for our flourishing: life. While what exactly human beings are scared of in their fears of death continues to be debated, what we are interested in this investigation is the link between our fear of death and flourishing. Philosopher Amélie Rorty expresses this as, *"what a person fears, in fearing death, often reveals what a person takes to be essential and prizeworthy in his life."*[494] In this chapter, when we talk about fear of death, we seek to identify what is essentially "prizeworthy" in the person's life, or in other words, what is important for the person's *eudaimonia*.

What will interest us in this section is whether the fear of death is situational or in the background, and how this focus can interfere with the person's flourishing. To further elaborate this topic, we will need to bring up the dirty little secret surrounding epilepsy: SUDEP. SUDEP stands for sudden and unexpected death for the person with epilepsy, and it is a phenomenon which continues to be largely unexplained by the medical community. SUDEP accounts for approximately 10% of deaths among people with epilepsy. A broad definition of SUDEP is, *"the unexpected, witnessed, or unwitnessed, death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus*[495]*, drowning or trauma, with no toxicological or anatomic cause for death found post-mortem."*[496] It is possible to die of a seizure.

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[494] Rorty, A.O., 1983. *Fearing Death*. Philosophy 58, p. 177

[495] A definition of status epilepticus is, *"status epilepticus is a neurologic and medical emergency manifested by prolonged seizure activity or multiple seizures without return to baseline. It is associated with substantial medical cost, morbidity, and mortality."* Pichler, M., Hocker, S., 2017. *Management of status epilepticus, in: Handbook of Clinical Neurology.* Elsevier, p. 131.

[496] Keddie, S., Angus-Leppan, H., Parker, T., Toescu, S., Nash, A., Adewunmi, O., Liu, R., 2016. *Discussing sudden unexpected death in epilepsy: Are we empowering our patients? A questionnaire survey.*

There is little to be done about SUDEP. Studies have found a few risk factors, such as non-stabilized epilepsy and those taking multiple combinations of anti-epileptic medications.[497] However, the largest risk seems to be seizures themselves. SUDEP thus represents a serious risk for all persons with epilepsy no matter the risk management strategy.[498] Because of SUDEP, but also other risk factors, epilepsy represents a considerable risk of premature death. Given its considerable consequences, it is certainly reasonable for patients (and in turn families and doctors) to be scared of SUDEP: the risk of sudden death shows the lack of control before our greatest fear. One day we are actively pursuing our life projects. The next moment, we are dead. Just like that. The sword of Damocles has fallen.

However, given that there is effectively nothing to do about SUDEP, other than trying to minimize or completely stop seizures, the person should probably not let this fear get out of hand and not let this fear of death affect their flourishing. Here we would like to explore the question of emotional risk that we have highlighted in the last chapter.[499] In other words, is it important that patients be aware of SUDEP, if there is nothing to be done? Will it not cause unhelpful — even destructive — fear for the person and the family to learn about the risk of sudden, unexpected death due to epilepsy?

Several empirical studies have attempted to grapple with the question of whether or not doctors should inform patients about SUDEP. However, the question continues to divide the medical community: when patients are solicited on this question, the answer is overwhelmingly yes, they wish to be informed, even if there are no preventive actions to reduce their risk. However, if we ask doctors, empirical research has shown that the answer is largely the opposite.[500] The most common factor cited by doctors for not informing the patient about SUDEP is the *fear* of causing patient distress by giving patients unsolicited

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[497] Sperling, M.R., 2001. *Sudden Unexplained Death in Epilepsy*. Epilepsy Currents 1, p. 21.

[498] One study on SUDEP concludes, *"progress will be made only as risk factors are defined and mechanisms of death elucidated…until then, physicians should strive to completely control seizures, since even infrequent seizures pose a risk of death." Ibid.*, p. 23

[499] At that time, we showed the emotional risk for the researcher herself in the study process.

[500] A literature review by Keddie et al. show that while patients – when asked – overwhelmingly want to be told about SUDEP, regardless of risk, doctors on the other hand, often hesitate to give this information due to perceived psychological stress. Another study identified by them show that only a minority of clinicians actually discuss this information. See: Keddie, S., Angus-Leppan, H., Parker, T., Toescu, S., Nash, A., Adewunmi, O., Liu, R., 2016. *Discussing sudden unexpected death in epilepsy: Are we empowering our patients? A questionnaire survey*. p. 2. It is to be noted however that this is not necessarily all healthcare provider's approach; the Teppe for instance does seek to inform patients about SUDEP. In France there also exists the Réseau Santé Mortalité Epilepsie (RSME) that gives information on SUDEP and helps families and healthcare providers in this difficult discussion.

information that they have little control over. Let us solicit a patient's point of view on this topic before trying to propose a suggestion for this dilemma in the doctor-patient relationship based upon our method *with* emotions:

> *"Every person who is diagnosed with epilepsy will have to, at one moment or another, confront himself with this idea. By superstition, by fear to seem bombastic, by anxiety especially, the patient only rarely dares ask his doctor, 'Will I die?' The question could sound like an insult to modern medicine. So, the question remains unexpressed. That is why the person with epilepsy tries to find out on his own…. but for many, as soon as they have decrypted the acronym, they prefer to no longer think about it, to erase it from their minds. It is even easier as no one, not even doctors, likes to talk about it."*[501]

From this citation, we can see that the difficulty in talking about SUDEP causes fear both for the patient (who wants to talk about it, but does not dare to), and for the doctor (who is reticent of discussing SUDEP because of the possible reaction of the patient). The result is that SUDEP largely remains an unspoken topic between the doctor and the patient. As the doctor's reticence to discuss SUDEP is not necessarily one of paternalism, but also of non-maleficence, this presents a dilemma for those in healthcare practice. We propose two arguments to help doctors with this question, one (fairly obvious) ethical argument and one based on Nussbaum's theory of emotions.

In the first place, not telling patients about dangerous risk factors related to their disease is a form of paternalism and largely unacceptable in today's societies (if not always by doctors because of the nocebo effect). If we return to the debate started in Chapter 1 of this thesis, favoring patient autonomy (through information sharing, etc.) is no longer choice, it is a professional obligation.[502] If doctors base their decisions not to tell based on possible manifestations of fear, they are once again deciding *for* the patient, not *with* the patient. So goes the rather obvious ethical argument; however, its importance is not to be discounted. In addition, we can argue that this is a testimonial injustice on the part of healthcare providers, who silence patients' viewpoints on the topics by avoiding it. This means that patients do not even have the possibility to engage in discussion about their fears with their doctor.

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[501] Researcher's translation of the French text. The author of this book is a YouTuber who has written his life story to try and help others and to raise awareness on epilepsy. Lafont, A., 2018. *Je suis Épilepticman*. p. 110-111.

[502] Beauchamp, Tom L., and James F. Childress. 2001. *Principles of Biomedical Ethics*. 5th ed. New York, N.Y: Oxford University Press. p. 63

However, given the necessity of taking into account non-maleficence, Nussbaum's theory can also help us answer this dilemma, in particular by considering background and situational emotions. As we discussed in the previous chapter, fear of death persists all of our lives, often in the background. It is brought to our attention when something happens to remind us of this fear. The moment the patient is informed is the moment when the fear is effectively "in focus" or to use Nussbaum's words, situational. However, the intensity of the situational fear is unlikely to persist in time. This intense expression of fear of death will eventually move into the background in some vague, less intense form. In addition fear of death by SUDEP does not appear to lead to many concrete, destructive actions on the part of the patient. An empirical study on this topic has for instance shown that patients who are informed about SUDEP by their doctors do not necessarily use this information for any concrete actions: instead they largely react to the information with a degree of fatalism.[503] From this point of view, there is no reason not to tell the patient, if we are to take into consideration the patient's desire and right to know about their disease.

In addition, if we take seriously the idea that emotions are cognitive evaluations, showing something important for the person's flourishing, then we can accept that it is reasonable for patients to be afraid of hearing this news. These are not overly emotional reactions. Instead they show the doctor that this represents something important for the patient (their life!) and the possibility for the doctor to mitigate these fears through open and honest communication, rather than hiding because of fear of their reaction. Healthcare professionals can even help move the patients move these fears to the background through open communication.

As we have said, the very intensity of an emotion such as fear shows that it is unlikely to persist in time, or at least that it will fade into the background. This is a problem if it means that patients will in turn become fatalistic or passive in the face of their disease, but one factor does not necessarily correlate with the other. After all, the sudden unexpected death possible from high-risk sports does not stop people from practicing them. In fact some rather hopeful actions may come out of learning about SUDEP. Our consciousness of our own corporeal limits can either become a factor to prevent action, or

[503] The solution suggested by the authors is that it forms a part of rather than a separate communication for recently diagnosed epilepsy patients. Keddie, S., Angus-Leppan, H., Parker, T., Toescu, S., Nash, A., Adewunmi, O., Liu, R., 2016. *Discussing sudden unexpected death in epilepsy: Are we empowering our patients? A questionnaire survey.* P. 6.

one which is dynamic, even stimulating.[504] Because we seek to limit uncertainty in our lives, such news can lead us to actions to mitigate risk. Since fear of death is so fundamental for the person's flourishing, including SUDEP as part of overall disease management discussions may provide the impetus for patients to take their epilepsy seriously, to find ways to manage their seizures and risk factors. In addition, it can also help other patients. Patients for instance can use this information to help others during seizures by altering medical staff or putting the patient out of danger.[505]

Thus, we maintain that this particular fear of death (due to the additional risk factor of having epilepsy) is not something to be ignored. The very intensity of the emotion shows its salience for the person concerned. As we have seen from the patient's example, both out of respect for their physician and general fear about the topic, it is unlikely the patient will bring up the topic during the discussion. However there is no reason to hide this information from patients, either from the ethical standpoint or because of the way the emotion may surface when the doctor gives the information to the patient, especially as it can help the patient take her disease seriously and mitigate against other risks. Indeed, this fear of death is not that different from every person's fear of death. In other words, patients and doctors are not so different. Taking the patient seriously in their fears also means giving doctors a space to express this vulnerability in themselves. We will return to this idea when we discuss fear in the doctor-patient relationship.

3. Fear of Inadequacy

Fear of death and fear of the body remain serious blocking factors for patients to flourish in society with their epilepsy; however, in this section we will investigate what is perhaps the most pervasive, invasive, and destructive fear in the life of patients with epilepsy: *fear of inadequacy*. We use this general term taken from Bauman's conception of life in liquid societies and how do-it-yourself fear has become the norm in a society based upon individual performance. However, we cannot really maintain that the PWE has fully been released, either, from the fears of nonconformity present in what Bauman refers to as the solid societies, in which the raison d'être was obedience, law, and obligations.[506] Indeed, the fear surrounding epilepsy seems a mix of both, a borderline between the fears

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[504] Bauman, Z., 2007. *Le présent liquide: peurs sociales et obsession sécuritaire.* Seuil, Paris. p. 76
[505] An example of this from our project was a patient learning first aid in order to help other epilepsy patients.
[506] Bauman, W. 2017. *"Afterward."* In Bordoni, C., 2017. *State of fear in a liquid world*, 1 Edition. ed. Routledge, Taylor & Francis Group, London ; New York. Bordoni, C., 2016. p. 112

present in the discipline society as immortalized by Foucault and the new anxieties coming from performing in an uncertain age.[507] The desire to conform is most evident in those who simply do not conform: borderline cases therefore can show us the limits of conceptions as Bauman's. When we examine society's fear, we see that society still expects the PWE to conform. In order to be accepted into the game itself, players still expect a certain amount of conformity to the rules in order to play. Thus, we disagree with Bauman that "fear to conform" has been fully "replaced" by "do-it-yourself fear." We propose instead that there are just more rules and that these rules have been given to the individual specifically.

In terms of our project, if anything, this desire to conform shows us an unavoidable fact in terms of our flourishing: our need for others and for society. Accepting differences in others seem to be a necessary element to allow persons such as those with epilepsy who do not "conform" fully to the rules of the game to be able to live and "perform" successfully in society, as otherwise they will be stigmatized (more on this in the next section). Now however, we will look at the individual PWE's desire to "perform" in today's liquid societies and what this means for their ability or inability. To illustrate this idea, we have chosen a narrative from our research in China, to show that this desire for performance is not only be a feature of so-called "Western" societies, but remains persistent — and devastating — in many societies.

Mei Ling's Story

Mei Ling, a 35-year-old woman from Shanghai, arrives at the prestigious Huashan Hospital in the French Concession on a hot June afternoon, accompanied by her mother. The hospital has no air conditioning in the outpatient clinic, so we go out to the classical Chinese garden for the interview, a tranquil space for patients and doctors alike with willows and Japanese maple trees arching over stone bridges and small ponds. With the sound of rushing water behind us, she and her mother tell me her story.[508]

This young, dynamic woman is haunted by her epilepsy which she has suffered from since she was 16. She immediately said to me that she cannot "tell" her epilepsy at her workplace. Her boss has understood that she has a health problem. He is kind and gives her holidays to go to her doctor's appointments. However, she doesn't dare tell him that she has epilepsy: she says that he finds out, she will have to quit. Her colleagues are less understanding. While they have understood that she has some kind of health problem, they don't know what it is. As she often has to leave early, or misses work for doctor's appointments, they call her "privileged." One of her colleagues has even stopped talking

[507] Bauman says these new raisons d'être in the liquid societies are liberty, desire, and a penchant for satisfaction. *Ibid.*

[508] The interview was conducted through translation (Chinese – English) by two student doctors working in the neurology department and involved in the social club organized at the hospital in June 2018.

to her: she describes being at work as "feeling like she is dead." Her mother says she is depressed and takes it out on her family by being aggressive.

Her doctor said the cause of her epilepsy was likely thyroid troubles[509]*; she had thyroid surgery ten years ago, but instead of curing her epilepsy, it has only gotten worse. She doesn't trust many doctors these days.*

Her epilepsy is relatively unsevere although refractory. She has relatively minor focal seizures[510] *in which usually she does not lose consciousness. The seizures themselves only last a few seconds and she recovers quite fast afterward. When things are really bad, she can have up to three a day, but usually she has much less. Her colleagues have never even noticed when she has had a seizure at work. She has learned when to expect her seizures and has adopted coping strategies: as she knows that seizures make her tired, for instance, she lets herself do easier tasks at work until she has fully recovered.*

The anti-epileptic medication she is taking seems almost worse than the seizures: as they interfere with her concentration[511]*, she has already had to change careers. She used to be an accountant, but as she cannot concentrate on the figures because of the medication, she decided to become a social worker. This less prestigious job has disappointed both her and her family. The hobbies she enjoyed doing — such as drawing and music — have been much harder since starting the medication. Her mother even thinks that they are responsible for her depression.*[512]

All of these factors have spiraled. She has isolated herself from her old friends, and she says she doesn't want to get married. Yet she is afraid of being alone. She brought her mother along to the interview because she no longer feels like she can go outside by herself. In turn, the impact on the family is immense: they worry about her depression, about her inability to find a partner, about her behavior toward them. Her mother describes the social pressure felt by her daughter in society like a "boomerang": the aggressive behavior she feels from her colleagues returns back to the family, as she becomes angry with her parents. The parents themselves have no one to talk to about their daughter's epilepsy as they do not want it to be known by their neighbors. While the mother said that she was concerned about the impact of epilepsy on her daughter, she keeps going back to the impact of the disease on the family as a whole. The mother tells me several times that she is really upset about her daughter's comments like, "why did you give birth to me? If you didn't, I wouldn't have the disease!" As their daughter is their only child, the parents have started to worry what it will be like for her when they are gone.

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[509] There is a possible correlation between thyroid dysfunction and epileptic seizures. For more information, see: Tamijani, S.M.S., Karimi, B., Amini, E., Golpich, M., Dargahi, L., Ali, R.A., Ibrahim, N.M., Mohamed, Z., Ghasemi, R., Ahmadiani, A., 2015. *Thyroid hormones: Possible roles in epilepsy pathology*. Seizure 31, 155–164.

[510] A focal onset seizure usually starts in one side of the brain. Symptoms vary depending on the part of the brain affected. Many patients do not lose consciousness. These types of seizures are also called "partial seizures."

[511] A known side-effect of the AED she is taking.

[512] Another known side-effect of the AED she is taking. In China it is a professional obligation for doctors to tell information on side effects to patients. However, given the short time for consultations (usually between 5-15 minutes), it is unlikely that the doctor is able to give much information on side effects. This comment by her mother is likely based upon personal experience of the side effects of the medication.

The one bright spot in this young person's life is "the "Seahorse Club," an epilepsy group organized by nurses and doctors at Huashan Hospital, where she has met many patients like her. The group is trying to empower patients to learn more about their disease and to gain a "positive attitude." Mei Ling says that while learning about the disease is important, she thinks the group should focus more attention on changing society's attitudes.[513] *Otherwise she and patients like her cannot really have a "positive attitude" because they face such severe discrimination and the need to hide their epilepsy.*

We will look at Mei Ling's story to see what fears present in her life can tell us about herself, her relationship with others, and to her flourishing. To return to Bauman's proposal, he says that in our highly individual societies, "*the spectre hanging over a society of would-be performers by-decree is the horror of finding oneself deficient — inept and inefficacious; as well as its immediate effects — loss of self-esteem and its perspective sequels — outcast and seclusion."*[514] In Mei Ling's story, the self-imposed fear, the self-imposed social isolation and self-stigma were prevalent throughout her story. Both her boss and her colleagues are not aware of her epilepsy, yet she is scared of telling them; her fear of others' reactions has prevented her from making friends and finding a partner. In turn this fear has filtered down to her family. Mei Ling is of course scared of not conforming to society's expectations; however, many of these fears are self-imposed.

The topic in which Mei Ling started our discussion, and returned to repeatedly during the interview, was her work and her toxic relationship with her colleagues. The main means in which we have today to assess our adequacy or performance is in the world of work. Our identities have increasingly been evaluated through our career choices and many of us now see the capacity to perform in our careers as essential to our flourishing. Society and familial expectations remain an important part of the pressure that we put on ourselves, as Mei Ling's story highlighted, but as she has also highlighted, we are also interested in how we stack up against others. Mei Ling did well in school and she had a high performing job but had to change careers due to her disease and the side effects of her treatment. Her new job as a social worker is less esteemed by herself, society, but also to

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[513] One way to do so would be to change the name of epilepsy: in Chinese, epilepsy is known as "goat's disease" (*dian-xing*). The word is associated with madness and bizarre movements of goats or pigs. It has correlated in society's vision of epilepsy as associated with psychiatric illness. Patients have successfully changed the name in Hong Kong, but not (yet) in mainland China. For more on other problematic formulations of epilepsy in East Asian countries see: Kim, H.D., Kang, H.-C., Lee, S.A., Huh, K., Lee, B.-I., 2014. *Changing name of epilepsy in Korea; cerebroelectric disorder (noi-jeon-jeung ,뇌전증,腦電症): My Epilepsy Story.* Epilepsia 55, 384–386.

[514] Bauman, W. 2017. *Afterward.* In Bordoni, C., 2017. *State of fear in a liquid world*, 1 Edition. ed. Routledge, Taylor & Francis Group, London ; New York. Bordoni, C., 2016. p. 113

her family who regret that she had to make this change. Thus she already is not performing — at least in her family and in her own eyes — in the choice of her career.

However, added on to this is her perception of her lack of value in the eyes of her colleagues, as she stays fewer hours than her colleagues. Even though she has found strategies to enable her to work in spite of her condition and the relatively short duration of her seizures permit her to hide these moments of lack of control from her colleagues, her incapacity to perform as many hours as her colleagues at work causes tension. She describes being at work as "being dead": by this she means that she does not have real relationships with her colleagues, that they ignore her, that they treat her as if she is invisible. Even though she can identify the object of the tension, and its importance to her, she is still too scared to tell them about her epilepsy.

This example illustrates Bauman's theory of "do-it-yourself" fear. However how much of Mei Ling's fear is justified — and how much is self-imposed — is hard to unravel. She does not tell others about her disease because she is aware of society's stigma; yet she can only blame herself, as she has not told any of her colleagues. The idea that she may get special privileges, that she does not have to "perform" to the same level and expectations as other colleagues[515], brings her considerable workplace tension; the reaction to these fears has been to isolate herself from her colleagues, but also in relationships outside of work. As we can see from Mei Ling's case, this fear is at least partly self-inflicted. This is a particularly dangerous combination for the PWE who faces another stigma coming from society, as we shall soon see. As Bauman has highlighted, it is expected in our performance societies that we both apt and efficacious. However, the new element in this discussion is our self-imposed seclusion, stigma, lack of performance, and the ensuing damage it has on individuals themselves, who can only "blame themselves" when they are excluded or ejected from the workplace. For Mei Ling, however, her flourishing was not only a question of having a high-performing career; it was also a question of having relationships with her colleagues. In turn, her other opportunities to

[515] Mei Ling's capacity to work in spite of her epilepsy remains a dream for many PWE. Due to problems with fatigue, concentration and memory problems, risks to themselves and others, but also stigma, the rate of unemployment and underemployment for PWE exceeds the general population. In China, which does not have a comprehensive healthcare system in place, the economic as well as social burden of epilepsy remains a significant factor keeping persons with epilepsy from flourishing. In countries such as France with more developed social safety nets, it continues to affect patients from an economic and social perspective, because they must rely on minimum social assistance if they are unable to work. For more information on unemployment and underemployment for PWE, see: Fisher, R.S., Vickrey, B.G., Gibson, P., Hermann, B., Penovich, P., Scherer, A., Walker, S.G., 2000. *The impact of epilepsy from the patient's perspective II: views about therapy and health care.* Epilepsy Res. 41, p. 53.

flourish (in her hobbies, with family and friends) were impacted by her incapacity to perform in the workplace. Thus these fears have repercussions in all of the patient's life.

This last fear is the most pernicious of those fears. It could be tempting to put all of the responsibility on the individual for their self-imposed stigma; for instance, we could propose that Mei Ling is wrong to keep her epilepsy from her colleagues. However if we take seriously Nussbaum's proposal of emotions as cognitive evaluations, the object of the fear is not unreasonable, but rather an assessment of the person's place in that world. It is unlikely that Mei Ling's fear has come from nowhere. In turn, following Bauman, we need to resist the urge to blame this on the individual.

Preliminary Conclusion

Through these three fears present in the life of the PWE, we have seen major impediments for the PWE to flourish in society. While some of these fears are mostly in the background, others have a major impact on our patients' flourishing as they lead to actions like self-imposed stigma and isolation. However, there are some reasons to hope, as we have already found several potential solutions:

Table 7: The Patient's Fear and Possible Solutions

Fear	Proposition of solutions	Reason for proposition
Fear of the body	Acceptance	Helps the PWE gain control of body and life projects
Fear of death	Doctor-patient communication	Helps move the fear into the background; may help the person take epilepsy seriously
Fear of inadequacy	Allowance for adjusted work environments; trainings for managers and colleagues	PWE may need adjustments to flourish in the workplace. This accommodation will likely come from the institutional level to be stable but can also be helped by trainings in the workplace

However, to fully tackle this fear, we will need to investigate Mei Ling's environment. We will need to investigate those relationships fundamental for her flourishing: the doctor-patient relationship, the family, and her relationship with society, in order to propose some possible solutions.

2.6.2. Society's Fear

In this section, we will investigate society's fear of the PWE. Society's fear results in disgust, stigma, and marginalization for our patients. It leads to shame by persons with epilepsy about having the disease. As Hume already noted, *"we are ashamed of such maladies as affect others, and are either dangerous or disagreeable to them. Of the epilepsy; because it gives a horror or to everyone present; Of the itch; because it is infectious: Of the king's-evil; because it commonly goes to posterity…men always consider the sentiments of others in the judgements of themselves."*[516] Society's fear of epilepsy affects our patients capacity to flourish and is therefore of our particular concern.

By suggesting links between fear and actions, we are not suggesting that they will *necessarily* result, nor that they have to[517]; on the contrary, as we will see, stigma and disgust are learned; thus they are also possible to change. However, fear, as a particularly strong emotion, gives impetus to act, and we are particularly interested in what kind of actions these fears encourage. We will put these fears — and the resulting disgust, stigma, and marginalization — through the lens of sociological insights to help us understand the particular challenges facing the person with epilepsy today, especially in the workplace.

However, in order to understand just how pervasive is the link between fear, stigma and disgust is in epilepsy, it will be useful to first show how epilepsy has been represented, understand, and lived throughout history. As one of the oldest known diseases, epilepsy has a long, rich, and disturbing history, one in which PWE have not only been stigmatized, but also exterminated. These historical scars continue to haunt our patients today; representations of epilepsy as sources of contagion or possession persist in the popular imagination, as we already saw in the theatre piece. Therefore it will be useful to briefly stop by the history[518] of epilepsy to understand just how pervasive and dominating society's fear has been — and remains — in society's imaginary.

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[516] Book II, Section 8, *On Beauty and Deformity*. Hume, D., Selby-Bigge, L.A., Nidditch, P.H., 1978. *A treatise of human nature*. Clarendon Press ; Oxford University Press, Oxford; New York. p. 303.

[517] Nussbaum says that, *"emotions are closely connected with action…and yet it would be a mistake to identify them with desires for particular types of action. Emotions direct us to an important component of our well-being and register the way things are with that important component…concrete fear prompts evasive action, or at least a desire for it…but not all emotions suggest a definite course to follow."* Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 135

[518] This history is largely a "Western" history; although there exist historical studies on traditional Chinese medicine's characterizations of epilepsy, how these texts influenced social practice are limited in international literature. We can only relate in confidence to what the fieldwork conducted in China reveals

Fear of Epilepsy in History

The first medical writings on epilepsy date from the Akkadian language (around 2000 BC) showing us imaginary representations of epilepsy as *antasubbû* (the hand of sin), brought by the moon.[519] Similarly, we can find epilepsy described in the Egyptian papyrus and the Babylonian cuneiform tablets, in which epileptics were described as diabolic spirits.[520] However it was the Greeks who coined the word epilepsy (*epikgwia*), coming from the Greek verb *epilambanein*, meaning "to seize, to possess." From this etymology, we can already see the association of seizures and possession. Greeks considered epilepsy as a miasma (pollution or bad air) that was thrown on the soul of sinners.[521] Epilepsy in Greek society was given to those who sinned, but was also contagious and to be avoided.

The first description in Greek society of epilepsy as a disease of the brain was given by Hippocrates, who wrote *On the Sacred Disease*[522] around 400 BC. With his work, he tried to combat superstitions that perpetuated the idea of a sacred disease for others' gains. However, Aristotle's connection between epilepsy and "intermittent badness" had more influence on society's perceptions of epilepsy than Hippocrates. In his *Ethica Nicomachea*, he connects virtue with deliberate actions that can either be natural or produced by habituation.[523] He reproaches incontinence (*akrasia*)[524] which links us to other animals.[525] In Book VII, he claims that self-indulgence is worse than incontinence, as the self-indulgent man has no regrets (he is merely pursuing his pleasure). He claims that, *"wickedness is like a disease such as dropsy or consumption, while incontinence (akrasia) is like epilepsy; the former is a permanent, the latter an intermittent badness."*[526] Unlike vice, which is willed, the intermittent bad of incontinence (epilepsy) cannot be taught.[527]

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about these representations today; thus we will have to content ourselves in this section to an admittedly non-inclusive Western-centered version of the historical representation of epilepsy.

[519] Magiorkinis, E., Sidiropoulou, K., Diamantis, A., 2010. *Hallmarks in the history of epilepsy: Epilepsy in antiquity.* Epilepsy & Behavior 17, p. 103.

[520] An exception to these imaginary representations in Antiquity is in ancient Indian medical writing, where Atreya described epilepsy as a cerebral dysfunction and not a divine intervention. *Ibid.* p. 104.

[521] *Ibid.* p. 104

[522] Masia, S.L., Devinsky, O., 2000. *Epilepsy and Behavior: A Brief History*. Epilepsy & Behavior 1, p. 27.

[523] Aristotle, Ross, W.D., Brown, L., 2009. *The Nicomachean ethics*. Oxford University Press, Oxford ; New York. Book VII, Book VII 9. p. 132

[524] Lack of self-control or self-mastery. *Ibid.*, Glossary, p. 269

[525] *Ibid.*, Book III. 2, p. 41

[526] *Ibid.*, Book VII, 1151a. p. 131

[527] He says that, *"now, since the incontinent man is apt to pursue, not on conviction, bodily pleasures that are excessive and contrary to correct reason, while the self-indulgent man is convinced because he is the sort of man to pursue them, it on the contrary the former that is easily persuaded to change his mind, while the later is not…such a man as this, then, is temperate; the contrary type is the self-indulgent." Ibid.,* Book VII 9, p. 132.

This largely negative conception of epilepsy, one that connected it to moral character, was largely influential until the Middle Ages.[528] However, the sequelae of the link between epilepsy and character can also be seen in later theories of the epileptic personality.[529]

These ideas about epilepsy became the means to stigmatize and discriminate. Stigma can already be seen in Plato's *Laws* which allowed the return of a slave if the epileptic seizure happened within one year of the slaves' purchase.[530] Greek and Roman medical texts describe epilepsy with disgust, in particular the tonic-clonic form.[531] In the Roman period, it was common to spit on persons with epilepsy to send back the contagion.[532] This stigma led persons with epilepsy — and their families — to hide their disease, a reflex that has not disappeared today.

In the Middle Ages, possession and witchcraft became associated with epilepsy; diagnosing and treating possession became the principal treatment.[533] The *Malleus Maleficarum*, the book written by two Dominican brothers in 1494, said that witches had certain characteristics, such as seizures, but also that they could cause epilepsy. While the actual figure remains contentious, historians estimate that this led to the execution of between 100,000-1,000,000 women during the Middle Ages.[534]

During the Renaissance, while the theory of Hippocrates of epilepsy as a disease and not a malediction returned, the continued difficulty of finding a specific epileptic lesion and effective treatments for epilepsy[535] added to recurring superstitions. New ideas about epilepsy followed the ideas of the time, with more misunderstandings to come. In 1770 Tissot claimed that epilepsy caused sexual excess and strong emotions such as fright or excessive mental worries.[536] In the 19th and 20th centuries, the idea of an "epileptic personality"[537] appeared and was associated with family tendencies such as madness,

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[528] Magiorkinis, E., Sidiropoulou, K., Diamantis, A., 2010. *Hallmarks in the history of epilepsy: Epilepsy in antiquity*. Epilepsy & Behavior 17, p. 106.
[529] The epileptic personality can already been seen from Antiquity in medical texts such as from Aretaeus of Capadocia's *On Epilepsy*. Reference cited in: Magiorkinis, E., Sidiropoulou, K., Diamantis, A., 2010. *Hallmarks in the history of epilepsy: Epilepsy in antiquity.* Epilepsy & Behavior 17, p. 106.
[530] Plato allowed an even greater time for epilepsy than for consumption or disease of the stone, which allowed only a 6-month window. *Ibid.,* p. 106.
[531] Masia, S.L., Devinsky, O., 2000. Epilepsy and Behavior: A Brief History. Epilepsy & Behavior 1, p. 28.
[532] *Ibid.,*, p. 28
[533] *Ibid.,* p. 28.
[534] *Ibid.,* p. 28.
[535] *Ibid.,* p. 28.
[536] Devinsky, J., 2007. *A diary of epilepsy in the early 1800s.* Epilepsy & Behavior 10, p. 309.
[537] The idea of the so-called "epileptic personality" is that there is a characteristic set of behavior characteristics of the person with epilepsy. This idea evolved from a combination of stigma, misunderstanding, and behavioral changes occurring from other disorders. *Ibid.,* p. 31.

alcoholism, violence, and criminal behavior.[538] During this period, the public debated whether or not epileptics should be responsible for crimes committed before or during their seizures.[539] While some believed that an epileptic personality could be the result of neurological factors, others thought that these behaviors were the very basis of understanding the person. When the first asylums were created in the 19th century, PWE were among the first patients. Within the asylum, the fear of contagion persisted, and this fear led to a second segregation within the asylum between epileptics and the general psychiatric population. In France Bouchet, Cazauvieihl, and Lauret did studies on the epileptic populations in these asylums and hypothesized causes such as fear, fright, drunkenness, pregnancy, and heredity,[540] adding new ways to stigmatize epilepsy (as well as new connections between fear and epilepsy).

The positive side of this isolation in asylums was that it allowed the development of the first pharmaceutical solutions for epilepsy, allowing persons with epilepsy to control their seizures for the first time.[541] However, making seizures disappear for some did not stop the stigma. While specialized institutions in epilepsy were created in the 1860s in Germany, the Netherlands, England, and in France, these institutions were geographically isolated from large city centers, the fear of contagion still present.[542] In the United States, legal barriers to marriages of persons with epilepsy persisted until the 19th century due to fear of passing down the epileptic gene. This vision was extended in the 20th century under the eugenic movement. In the 1900s, in the United States, epileptic colonies were created in several states and forced sterilization before and after World War II also led to sterilization. During the 1950s, restrictive laws were extended for driving, marriage and reproduction.

This non-exhaustive history highlights a persistence of fear in the representation of epilepsy: fear of contamination, fear of passing on the disease to future generations, fear of epilepsy as some kind of psychiatric, personality, or nervous disorder. Throughout history, fear of persons with epilepsy has led to their stigma and isolation. Is it no wonder

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[538] *Ibid.*, p. 305

[539] A discussion that partly continues today in determining whether or not harm committed during seizure is the person's responsibility.

[540] Sidiropoulou, K., Diamantis, A., Magiorkinis, E., 2010. *Hallmarks in 18th- and 19th-century epilepsy research*. Epilepsy & Behavior 18, p. 152

[541] The first of these was potassium bromide (1859), a medical sedative. In 1938, phenytoin showed its capacity to control seizures without a heavy sedative effect. Rho, J.M., White, H.S., 2018. *Brief history of anti-seizure drug development.* Epilepsia Open 3, 114–119. p. 116

[542] de Boer, H.M., 2010. *Epilepsy stigma: Moving from a global problem to global solutions*. Seizure 19, p. 633.

then that families and persons with epilepsy have sought every possible means to hide their disease? From this short historical narrative, we can identify two pervasive trends in the popular (imaginary) representation of epilepsy throughout history: 1) the fear of contamination through bodily fluids, touch, genes, etc. and 2) seeing epilepsy as somehow "bad," linked to excess or the lack of control. These representations have led to various forms of punishment in history, but they can also be seen today in new forms and imaginaries (as we have already seen with Mei Ling in her workplace). We will explore both of these themes in relation to our subject.

1. Fear of the Body and Death

In our theatre play, "Epilepsy and Prejudice," we saw a representation of fear of contagion. The scene was of course exaggerated for dramatic effect, but it was developed based upon the real-life experiences of the actors. Many people[543] throughout the world continue to fear epilepsy due to a fear of contagion. This scene could have happened in Ancient Greek society, in a 19th French century asylum, but instead it took place in our contemporary world. We propose that following Nussbaum's link of fear and disgust, society's continued fear of epilepsy can be explained (at least partly) by this ongoing fear of contagion. By contagion we mean both *bodily contagion* (i.e. catching the disease in some way in a body-to-body transmission) but also *figurative contagion* (i.e. somehow related to the idea of becoming the sick person one day). We will be discussing this *figurative contagion* with the help of Freud's conception of *uncanny*.

Fear and Disgust

Nussbaum says that all societies marginalize or subordinate some groups of people.[544] One of the ways to do so is through disgust. Nussbaum says that disgust, *"is motivated by anxiety about animality and mortality, and triggered, therefore, by bodily characteristics, real or imputed, that bear a close relationship to our anxieties about mortality and the vulnerable human body."*[545] Disgust is a bit different to fear. Although it

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[543] But not animals; dogs, cats, and other animals often instinctively try to protect and soothe those with epileptic seizures and their potential for helping persons with epilepsy to get out of danger during a seizure is increasingly being promoted. See for instance: Catala, A., Cousillas, H., Hausberger, M., Grandgeorge, M., 2018. *Dog alerting and/or responding to epileptic seizures: A scoping review.* PLoS ONE 13, e0208280.
[544] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. p. 97
[545] *Ibid.*, p. 98

may alert us to danger (attention, this may be poisonous!), many dangerous things are not disgusting, while many disgusting things are not dangerous.[546] Nussbaum says that disgust is linked with the imaginary (our imagined projection of that object), as well as to contact with "that disgusting thing." Disgust is an aversion to contact that is motivated by a thought of contamination.[547] Although the feeling of disgust can be related to danger (do not eat that fecal matter!), it is also an imaginary idea of passing the object of contamination inside your body.[548] This imaginary of contamination is important to our project, as it leads to fear of the object, and disgust and stigma to avoid the (imaginary) danger of that object.

Nussbaum calls "primary disgust" those reactions to bodily excrements and other bodily fluids which are both disgusting to humans and to other animals. Many of these disgusting traits may appear during a seizure: some patients salivate, while others urinate or bleed. The epileptic seizure in certain persons, such as those experiencing tonic-clonic seizures, can also seem animalistic: it involves involuntary bodily movements, such as thrashing, squealing, or moving in an uncoordinated, chaotic way. In traditional Chinese medicine, epilepsy is known as the *goat's disease*[549] due to these sounds and involuntary bodily movements. Thus witnessing some (not all) seizures bring us back to our animal natures. We are both disgusted by the products of our animality (our bodily odors and secretions), but also by the transformation of man into animal (the "screeching goat").

All of these reactions to these animalistic movements and sounds, however, show us something important about ourselves: our shame in our own helplessness, our vulnerability, in short our animal natures. Nussbaum says that human beings are alone in the animal kingdom to be anxious about being animals and will do anything to transcend it. Therefore things that remind us of our true animal natures are seen as disgusting.[550] Fear of the object stems from this recognition of our link to other animals but also to our shame of these animal origins. The fear of the person with epilepsy is therefore a basic, survival fear, but is also related to our shame of our animal bodies and our lack of control of them.

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[546] *Ibid.*, p. 104
[547] *Ibid.*, p. 105
[548] *Ibid.*, p. 105
[549] Lau, K.K., Ng, P.W., Chan, C., Lui, C., Huang, C.Y., 2011. *Announcement of a new Chinese name for epilepsy: GRAY MATTERS*. Epilepsia 52, p. 420.
[550] Nussbaum quotes here Frans de Waal's concept of "anthropodenial" by which she means denial of membership in the animal species. Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. p. 107

However it is not just our animal natures that we are afraid of; Nussbaum proposes that we do not feel "disgusted" by all aspects of humanity. Instead we are disgusted by what we think as base, especially that which reminds us of death or decay.[551] Thus disgust stems not only from *fear of the body* (and its lack of control) but also due to our primitive *fear of death*. According to Nussbaum, "*it (disgust) is a fear that somehow pertains to death and our potentially decaying embodiment, and that is what makes it operate through symbols, rather than sensory properties. We are quite literally refusing to ingest decay, hence to be 'dead.'*"[552] Disgust is thus about avoiding death and decay, and it is a basic animal instinct that we can see across animal species related to our survival; however it takes on new, twisted forms in human society.

The Easy Solution: Projective Disgust

We have adapted complex adaptations of this basic fear of death and of our animal natures. If we are inherently afraid of being animals, especially because that means we will die, it can at times be soothing to think of others as disgusting, rather than admit this about ourselves. This leads to what Nussbaum calls "projective disgust": disgust felt by oneself when it is transferred onto another. Nussbaum says,

> *"If people can't keep entirely clear of the disgusting in themselves, they may be helped by a further stratagem that is all too common in human life…if we could identify a group of human beings whom we could see as more animals than we are, more sweaty, more smelly, more sexual, more suffused with the stench of mortality…if we could identify such a group of human and subordinate them successfully, we might feel more secure. Those are the animals, not us. Those are dirty and smelly, we are pure and clean."*[553]

Instead of encouraging equality or mutual respect,[554] disgust allows us to distance ourselves from the other person, to project our insecurity about our animality onto someone else — and thus far away from ourselves. Throughout history, up to the present day, we can see that PWE have been pushed to the margins, in many societies and cultures. Projective disgust has led to stigma[555] and marginalization for persons with epilepsy. Oaten

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[551] *Ibid.*, p. 105
[552] *Ibid.*, p. 105-106
[553] *Ibid.* p. 110.
[554] *Ibid.*, p. 116
[555] Goffman's definition of stigma is, *"an attribute that is deeply discrediting."* Goffman said that societies stigmatize physical deformities, blemishes on individual character, but also generational traits that can transmitted from generation to generation (such as race, nation, and religion). All of these justifications for

et al[556] have also proposed that stigmatization can be explained by the activation of a disease-avoidance system, irrespective of its accuracy. Visible disease cues (such as seizures) activate the idea of contamination, and in turn those who are stigmatized are those who evoke disgust and are contaminating.[557] This fear is fed by the uncertainty of the contagion due to recurring stereotypes and representations of epilepsy as contagious. Fear, leading to disgust, is therefore an evaluation of threat of disease to the person nearby. While it may not be an accurate understanding of the disease, it is an evaluation of danger. However the disease-avoidance system cannot be the only explanation for ongoing stigma toward our patients, although they are particularly vulnerable to this view because they may emit secretions during a seizure which could be viewed as "contaminants." As we saw with Bauman's analysis of our liquid societies, our increased world of insecurity has led to increased fears and scapegoating. In societies today, diseases like epilepsy represent a new lack of control among many other uncontrollable situations. Seizures — and the persons experiencing these seizures — remind us that of that uncertainty which we would prefer to forget.

Nussbaum adds that we are particularly prone to projecting our disgust onto vulnerable beings. She says that, "*when people feel insecure, they tend to lash out to blame and scapegoat the vulnerable…their tendency to project disgust outward is likely to rise to the extent that their own sense of bodily vulnerability and mortality rises.*"[558] This projective disgust and ensuing stigma has an impact on the ability of the person with epilepsy to flourish in society. As Bauman says, those living on the margins in today's societies have become not only "untouchable" but also "unthinkable" and even "unimaginable."[559] As we saw in the previous section, the PWE is already scared of their body and their inability to control it. When society mirrors that fear through projected disgust, it influences the person's already complex relationship with her body and with her epilepsy. Let us therefore pursue our investigation between fear and disgust by seeing what these actions can tell us about society's implication in a person's *eudaimonia*.

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stigma can be seen in the history of epilepsy. Goffman, E., 1986. *Stigma: notes on the management of spoiled identity*, 26th pr. ed., A Touchstone Book. Simon & Schuster, New York. p. 12.

[556] Oaten *et al*.'s definition of stigmatization is, *"chronic social and physical avoidance of a person by other people."* Oaten, M., Stevenson, R.J., Case, T.I., 2011. *Disease avoidance as a functional basis for stigmatization*. Philosophical Transactions of the Royal Society B: Biological Sciences 366, p. 3433.

[557] This is not only a characteristic of humans but also of the greater animal kingdom. *Ibid.*, p. 3433.

[558] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. p. 132

[559] Bauman, Z., 2007. *Le présent liquide: peurs sociales et obsession sécuritaire*. Seuil, Paris. p. 63

In the first place, let us look at the individual in society. A way to look at this subject will be to understand how the epileptic person herself witnesses another epileptic person's seizures. One would think that the PWE is the one with the most intimate knowledge of seizures, and thus the least likely to be scared when they witness one. However as many persons with epilepsy lose consciousness during the seizure, often their only access to this experience is by seeing another epileptic seize. This experience is fascinating for the epileptic — it is a phenomenological access to the world that is often missing in their own histories.[560] However many persons with epilepsy describe this experience as "scary" and "frightening"[561] just like the general public. These moments produce fear and anxiety for the witness. Not only is the means in which they can help the person often unclear, but it also shows something intimate and scary about themselves. While the PWE may ask themselves, *"is that me?"* is that *"what I look like when I have a seizure?"* the person without epilepsy may ask themselves, *"will I be next?"* Therefore while this emotion may be less intense for the person who does not have epilepsy, it still shows possibilities. It is a situation in which our innermost background fears of our body and of death move to the forefront. Our temptation as witnesses is back away from this fearful situation, to move it as far away from us as possible.

However, during this experience of intense, situational fear, we (as persons in society) are also expected to act, to touch the person having the seizures if necessary to move them out of danger. This is highly troubling to us, because added onto this responsibility is the imaginary fear of contamination *and* the unspoken violation of our social rules. Bauman in his book *Liquid Modernity* described our society's *non-spaces*, places where no one is at home, places of passage, where individuals must face strangers on a continuous basis (the airport, the metro, the supermarket). In order to mitigate against the uncertainty of these interactions, Bauman says that there is an expected amount of *redundancy of interaction* in these spaces.[562] However, the person experiencing the seizure is the person in crisis: she is calling for assistance, for support, for interaction. She is therefore committing a double transgression by not only violating the social rules but also

[560] During a rehearsal of our theatre troupe, when one person had a seizure, the group spent the next hour discussing and asking questions to the person who experienced the seizure. They mentioned several times that seeing the seizure was also "scary" to them and made them wonder what it was like for others when they themselves had a seizure.
[561] For this reason, many doctors decide not to show the videos of their seizures to the patients themselves.
[562] Bauman, Z., 2000. *Liquid modernity*. Polity Press ; Blackwell, Cambridge, UK : Malden, MA. p. 105

(in the imaginary) putting the person "at risk" of contagion, and we cannot say which of these factors is more frightful for the person witnessing the seizure.

Fear and the Uncanny

The person witnessing the seizure may not consciously attach a value to their experience of fear in this way, as it may incarnate a vague object. Nussbaum reminds us that, *"it is very important to insist that emotions often do have a vague object: a fear that one's projects will come to nothing, a hope for good events, a joy in things as they are. But there is still an object there, and the emotions are still hooked into my conception of what is worthwhile and important."*[563] What we can learn from this insight is that being scared of the epileptic person is not necessarily to be scared of that particular person, or even of their disease, but rather what they represent to the witness in terms of their life projects.

Freud's definition of the *uncanny* will help us to elaborate on Nussbaum's idea of a vague object of fear. Freud says the feeling of uncanny can be defined as, *"that class of the terrifying which leads back to something long known to us, once very familiar."*[564] In his article, Freud even mentions epileptic seizures as representing something uncanny, because, *"the ordinary persons sees in them the working of forces hereto unsuspected in his fellow man but of which he is dimly aware of in a remote corner of his being."*[565] The familiar yet terrifying aspect of the epileptic seizure shows us how fragile are those automatic bodily processes in the human body, those processes of which we are barely aware when we go about our life projects. Seeing the person in front of us whose body loses suddenly loses control is *uncanny*, as it reminds us of our own body's capacity — and even probability — to one day derail like the person seizing before us. And when the body will inevitably do so, the person can no longer flourish. This uncanny feeling thus reminds us of the insecurity of our lives and our projects, and the time limit on our ability to flourish within our vulnerable and extinguishable bodies. These experiences are frightful; they bring us back to our ongoing fears of death. To use Nussbaum's words, they bring the emotion of fear of death from the background into the foreground. Freud claims this uncanny feeling is one of *doubling*: if one person possesses the knowledge, feeling,

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[563] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 133
[564] Freud, S. 1919. *The "Uncanny"*. First published in *Imago*, Bd. V., 1919; reprinted in Sammlung, Funfte Folge. p. 1-2
[565] *Ibid*., p. 14

and experience in common with the other, his foreign self becomes compounded, resulting in a doubling of the self.[566] We will not take this suggestion by Freud literally, but we can see that the person seeing the seizure "sees" themselves in some way, perhaps not as a double, but as one who can experience something similar. In essence, the imaginary of our deepest fears become a reality[567] when we witness such bodily derailments in the other.

Boomerang Fears

We could perhaps allow that these uncanny, situational fears when seeing another epileptic person "seize" are permissible, or even inevitable, based upon our insecurity and desire to hide our animal natures, were it not for the influence of such emotion-beliefs on PWE themselves. As we have seen in the previous section, PWE need others to flourish, both when they are in a seizure, but also when they are just a regular person in society. As affiliation remains an important means for persons to flourish in society, a person with epilepsy cannot do so when "others in society" means an environment in which they are stigmatized, isolated, and even banned. While this must be difficult for any person who is stigmatized, this is in particularly dangerous for the PWE because it is an additional weight put on the person's own fear of their body, of death, and of their own inadequacy. Indeed, social and individual stigmas are so knotted together that most of the time, it is difficult to say which caused or followed the other (as we saw with Mei Ling).

The fear and disgust expressed by society in turn become complex, learned fears for the person with epilepsy, further impeding their flourishing in new, unexpected ways. As the PWE cannot control how the person in society will react to her epilepsy, they may seek to hide their epilepsy as a means of having a certain amount of control of the situation. It is a reasonable judgment that they should be scared to tell their epilepsy to others, when society stigmatizes the PWE. In turn, as society's assistance is uncertain, there is little to do to control the situation other than hiding it.

However, this fear can become destructive in other ways important for the person's flourishing. Nussbaum, paraphrasing Seligman, has linked fear and learned helplessness.[568]

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[566] *Ibid.*, p. 9
[567] *Ibid.*, p. 15
[568] Nussbaum says that learned helplessness comes when there is the expectation that an outcome is independent to the action. It 1) reduces the motivation to try and control the outcome; 2) interferes with learning to what one can do to control the outcome; 3) produces fear as long as the subject is uncertain of the uncontrollability of the outcomes, and in turn produces depression. Nussbaum, M.C., 2001. *Upheavals of*

She says that fear can become a particularly destructive emotion when instead of encouraging learning and adaptation to the environment, it instead produces a feeling of passivity or even renunciation. Thus fear becomes particularly harmful when it leads to new fears for the person, fears in new situations and with new persons in environments in which they have no reason to be afraid. For instance, fear experienced by a young boy's best friend can lead him in turn to hide details of his epilepsy from his doctors. One fear feeds another and every social situation can become fearful.

When meeting a new person, when on a date, when going to a job interview, the most common dilemma faced by the person with epilepsy is, "do I tell?" or "do I not tell?" Goffman says that "passing" off for normal induces a high level of anxiety, in living a life that can collapse at any moment.[569] As we have seen in the example of Mei Ling, she had some reasons not to tell her colleagues about her epilepsy, as she was scared of losing her job. That said, we cannot actually say what would have been the outcome, as she did not tell them about her epilepsy. For Mei Ling, her initial fear of her own epilepsy has become chronic, leading to paralysis in her daily life. It has even had a *boomerang effect* by affecting her family and other social relationships.

Following our Chinese research, we refer to these complex emotions as *boomerangs*, because they are fears initially experienced in one environment which returns to the original source in new, unexpected, and complex ways. For Mei Ling, the fear initially felt in the family about her epilepsy led to her being scared to tell her colleagues, which led to complex manifestations of fear, anger, and other destructive emotions to boomerang and affect the whole family in new, highly intense ways. In these *boomerang fears*, it remains difficult to understand if these fears are self-imposed, whether or not they are an inaccurate evaluation of the event, or whether past events have so conditioned the evaluation of the event that it is not possible to see clearly. In any case, these boomerang fears led to new fears and are particularly difficult to rectify.

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thought: the intelligence of emotions. Cambridge University Press, Cambridge ; New York. p. 103, quoting Seligman (1975), p. 55-56

[569] Goffman, E., 1986. *Stigma: notes on the management of spoiled identity*, 26th pr. ed, A Touchstone Book. Simon & Schuster, New York. p. 149

Fear and Eudaimonia

These boomerang fears show us the particularly destructive and complex nature of learned experiences of fear. However following Nussbaum, we will pay attention to the object of fear and what it can show us about the person's flourishing. If the person is terrified of telling her epilepsy to co-workers, that means that this relationship is quite important to her flourishing, whether or not an accurate evaluation of that situation. Thus we can understand that both the PWE and society's fears of the epileptic show objects of fundamental importance to them: life; the need to continue striving in spite of inevitable death; and the need to continue living in society, *with* and *toward* others, in order to flourish. The seizure puts into difficulty all of these things.

These fears become malicious when they are deformed and inaccurate evaluations of the object of the fear: or instance, the person seizing does not mean that the person next to them will ever experience the same event; likewise the person who was rejected by friends because of his epilepsy during his adolescence will not necessarily be rejected by friends in his adult life because of his disease. These *deformed evaluations* of fear can represent considerable danger for the PWE's flourishing, as they have become so twisted from their original object that we can no longer even identify the source of the original fear. Nussbaum claims that there are two categories of emotions, those whose borders are around oneself, and those that are outside oneself. Some emotions, such as hope, expand one's vision, while others, such as fear and disgust, draw boundaries.[570] Emotions such as fear and disgust lean inward and tend to isolate the individual. In turn, when they become deformed or boomerang, they become toxic both to the person and the environment around them. This means that fear is highly destructive for the *whole family* and calls for social action to identify what we can do to rectify this duress.

However, despite this opening, we do not have any easy solutions to propose to combat these fears emanating from society. Indeed, they so knotted in both society's and the person's fears that we have easily traced them to representations of fear and disgust from Antiquity. The ongoing reactions of fear throughout history suggest that these fears will be difficult to change without social transformations, especially as they are linked to some of our most intimate fears. For instance, even for families, who may know their family member's seizures, it is difficult not to be disgusted about bodily discretions, as we

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[570] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions.* Cambridge University Press, Cambridge ; New York, p. 300

are to a certain extent hardwired to avoid them. However, this enduring representation of death and decay does not mean that we cannot separate the individual person from their temporary bodily secretions. In order to do so, it will be necessary to dispel the continued idea of contagion, which persists despite scientific knowledge that epilepsy is a neurological disorder that is non-contagious (and for the most part, non-hereditary).

Here we can make a practical suggestion. Nussbaum reminds us that disgust is part of our evolutionary heritage; however, unlike fear, it is not part of lives until toilet training; thus while it has some links in our animal heritage (i.e. to avoid contamination for survival); it is also a taught emotion.[571] A taught emotion means that it can be at least partly overcome, given education. This means moving epilepsy out of the shadows, through actions such as daring to "tell" one's epilepsy to others in order to educate society and dispel these ongoing myths. As long as patients, doctors, and the family encourage the person with epilepsy to hide, it is likely that we (speaking as society and persons in society) will be continue to be scared. Epilepsy remains "interesting" "astounding" "frightening" because it is hidden and suddenly "appears" and "surprises" us, revealing our vulnerabilities. What we need is to combat that surprise, to make epilepsy ordinary, a reflection of its predominance worldwide.[572] As one doctor expressed during my research,

> *"We need epilepsy to become banal…what I mean by that is that is that we should speak of epilepsy as we speak of cancer, as we speak of AIDS…when we have patients that manage to make their disease banal, obviously they are better, often they have fewer seizures, there is less anxiety, they do not stress in thinking, 'tonight I am going to have dinner with friends, will I have a seizure?' as long as we do not trivialize epilepsy, they* (the patients) *will always live with the Sword of Damocles above their heads."*[573]

When the public sees a PWE in the street — it will considerably reduce their fear if they know that those involuntary bodily movements could be epilepsy. Similarly, if the person with epilepsy tells their co-worker how to handle their particular type of epilepsy, then they will be in turn less scared when they see the seizure, as they will have been told how to help them. Even though we have been to a certain extent trained to avoid communication and eye contact in our contemporary non-spaces, that does not mean that

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[571] Nussbaum, M.C., 2018. *The monarchy of fear: a philosopher looks at our political crisis*, First Simon & Schuster hardcover edition. ed. Simon & Schuster, New York. p. 102

[572] Epilepsy is the most common neurological disorder after migraine; there is a common saying among the epileptic community that if you have never met anyone with epilepsy, it is only because they haven't told you they are epileptic.

[573] Interview with a neurologist at the Teppe, May 2018.

we as humans do not wish to help, when our help can be useful, and especially to those with who we are in a relationship.

To be clear, we are not saying that society's fear is the fault of the person with epilepsy. On the contrary, their fear is largely an accurate evaluation of the historical and actual perception of their disease in society. However, in order to propose solutions, we will need to change society's perception, and this suggests an important role for education in minimizing fear. Because we cannot expect that people who have never met anyone (or never knew they met someone) to care enough to learn about the stigma surrounding the disease, overcoming fear of epilepsy will mainly be the combat of those most concerned (although social institutions can considerably assist). That is not to say that we should place all responsibility on these individuals (the individual responsibility as suggested by Bauman in today's liquid societies); it is not the fault, after all, of the person that society is scared. However, the first step to bring epilepsy out of the shadows means no longer concealing it. As we saw with Mei Ling, we cannot expect society to know what to do, or how to react, if they are not even aware. Indeed her colleagues disregard for her could merely be a misunderstanding. Stigma is both felt[574] and enacted.[575] In order to change both, it will be necessary to change social attitudes. As we are scared of what we do not know, then we can encourage those concerned to help society know,[576] to make epilepsy ordinary.

[574] The authors define felt stigma for epilepsy as, *"the shame of having epilepsy and fear of encountering with enacted stigma."* Aydemir, N., Kaya, B., Yıldız, G., Öztura, I., Baklan, B., 2016. *Determinants of felt stigma in epilepsy.* Epilepsy & Behavior 58, p. 76.

[575] The authors refer to this type of stigma as real episodes of discrimination against a person on the grounds of the person's condition (epilepsy, etc.). *Ibid.,* p. 76.

[576] This was the ambition of the theatre play "Epilepsy and Prejudice" formed with patients as part of this research project.

2. Fear of Inadequacy

Natalie's story

Natalie is a courageous young woman, with her full life ahead of her. Despite her epilepsy, she has big dreams. She has always wanted to become a chef and successfully completed a training to do so.

One year of searching for employment. One year of refusals. She has always been honest about her epilepsy and has always told her potential employers about it, especially as her epilepsy has stabilized. However, potential employers were always too scared of the word "epilepsy" to give her a chance.

Finally, through family contacts, she thinks she finally has had a break at a school canteen, where it will be fairly easy to adapt the post. She goes to the interview and comes out certain that she finally got an offer. One week later, however, she gets a letter saying, "we would really like to hire you, but we don't want to adapt the post."

After all these failures, she lost confidence in herself. It was then that her seizures started again. The seizures got so bad that her doctor recommended that she go to a special medical-social center for epilepsy, both to try and stabilize her epilepsy, but also to find a job and an employer who will accept her, who will "adapt the post" to her individual needs.

It has now been 4 years since that refusal letter. She is still at the medical-social center, trying to find a solution for her career and for her epilepsy.

In inspiration of Bauman's work in *Liquid Societies*, and Natalie's story, we propose that another fear that is keeping the epileptic from flourishing in societies is the inability to perform in today's workplace. However, as stated in the previous section, there is also good reason to believe that society has not fully transitioned from what Bauman called the *solid* societies, where there was an expectation not only to "perform" but also to "conform." Again epilepsy is the borderline case, as it so often bothers, frightens, and disturbs the public. If we are bothered about these types of involuntary behaviors, it is because we still expect some conformity in behavior. Violating these rules is still punished because of these social rules. Thus we have not fully exited these demands for conformity. However, what will interest us in this section specifically is what the fear of inadequacy in the workplace means to the PWE, and to society as a whole, in terms of their flourishing.

If there is a certain liberty of choice in our careers today, based on what "interests" us or what are our priorities (stability, money, or personal interest), it is in turn up to the individual to make the most of it, to excel, because of that individual choice. Of course our career choices are influenced by our social backgrounds, our family backgrounds, and our ideas of what the particular career will mean in our lives, but there remains a certain amount of choice in our career decisions today, at least for those with access to education.

And if we are unsatisfied for whatever reason, there is also the possibility to "change" "re-orientate" or "reinvent" ourselves in a new career. This gives a certain freedom, but also imposes a responsibility on the person to excel in their chosen working environment. Bauman states that, *"it is individual men and women on their own who are expected to use, individually, their own wits resources, and industry to lift themselves to a more satisfactory condition and leave behind whatever aspect of their present condition they may resent."*[577] That person who is expected to need more support is the non-autonomous individual, the non-capable, and the non-performing individual, the lazy one. It is her own fault that she has not succeeded. She merely needs to use her own resources to change her position, or to find an adequate solution, and the idea that she may need other people's help to do so is frowned upon in our liquid societies.

The PWE shows us the cracks in this worldview of unlimited individual possibilities for success. Due to the side effects of medication, due to the difficulties of the disease itself, the PWE cannot necessary perform to the same speed, pace, or level of performance as her colleagues, even with considerable personal investment and motivation. As we saw with Mei Ling, because of her medication, she had to change careers to a less concentration-demanding career; however, she still suffered in this new career. If people like Mei Ling are to do their jobs well, they will need some flexibility, some adaptation, but also social support from colleagues. Instead her colleagues are jealous of her time off and seek to isolate her because of it.

Bauman goes even farther. He says that in our age of *light* capitalism, the presence of labor has become secondary. Rather than a relationship of mutual dependence between the employer and the employee, what matters is the end result, the consumer and what the consumer wants.[578] Labor must be willing to provide the service to the consumer, but it does not really matter who that person is; hence people view their jobs as disposable while employers view their own workers as disposable. In turn, employers do not wish to be bogged down by difficult employees, by those who need to "adapt their post" or who need extra help. Rare is the employer who will see the person behind the consumer or who takes the long-term view.

Even if we accept this vision of job and employee disposability as proposed by Bauman, this does not take into account just how much our careers are tied to our sense of

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[577] Bauman, Z., 2000. *Liquid modernity*. Polity Press ; Blackwell, Cambridge, UK : Malden, MA. P. 135.
[578] *Ibid*., p. 139-140.

self and to our flourishing. As family, religious, and friendship ties become more fluid, we are still seeking some anchoring, and usually this is through our careers. We saw with Mei Ling just how much her career was tied to her flourishing: the suffering at work, and the boomerang fear she extended to her family showed just how important these relationships and the work itself was to her sense of self-worth and value. Even in the age of light capitalism, our careers remain the practical means for us to flourish in today's societies, to go to our limits, to see what we are capable of, to see what we can become. Those who do not perform in their careers are to a certain extent not flourishing because working remains a practical way for them to strive.

The constraints of epilepsy make occupational performance particularly challenging. This is both due to the disease (Mei Ling's case) as well as the stigma surrounding epilepsy (Nathalie's case). Numerous studies have linked epilepsy with higher rates of unemployment and underemployment, as well as greater difficulties in job retention.[579] Having epilepsy has also been correlated with higher unemployment rates, job layoffs, being declared "unfit to work", feeling shame for having the disease, and depression.[580] Within these statistics, it is difficult to unknot if these difficulties are a result of the disease itself, or whether they are a result of social stigma or self-stigma.[581] However what is evident is that these factors spiral together to make it particularly difficult for our patients to flourish in today's workplace, or even to have the opportunity to try.

In her story, Nathalie said that she felt stigma coming from the employers who wanted to hire her, not necessarily because she was epileptic, but because she was in need of adaptation, implying that she risked not being able to perform her job immediately. For the employer, epilepsy was viewed as a risk. Thus we say that we "found a better candidate", that "we couldn't adapt the post," but what we really mean is that we will only accept those at the top of their game, the performers that can start excelling right away.

As Bauman has shown, this situation of fear, coming from the risk of taking someone who may need extra help to be able to perform to the same level as the others, is not seen as the responsibility of the employers and their lack of desire to "adapt the post"; instead it is blamed on the individual person who experiences the stigma and

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[579] Smeets, V.M.J., van Lierop, B.A.G., Vanhoutvin, J.P.G., Aldenkamp, A.P., Nijhuis, F.J.N., 2007. *Epilepsy and employment: Literature review*. Epilepsy & Behavior 10, p. 354.
[580] de Souza, J.L., Faiola, A.S., Miziara, C.S.M.G., de Manreza, M.L.G., 2018. *The Perceived Social Stigma of People with Epilepsy with regard to the Question of Employability*. Neurology Research International 2018, p. 1.
[581] *Ibid*.

marginalization. The sociologist Bordoni showed us that while official exclusion is impossible in many societies today, personal (and we will add organizational) marginalization is thriving. In workplaces, those who are different, those who do not represent organizational values, are easily forgotten. The PWE is expected to adapt to the marketplace, not make the marketplace adapt to them.

As Nussbaum says, *"emotions…are acknowledgements of our goals and of their status. It then remains to be seen what the world will let us do about them."*[582] The environment of fear surrounding epilepsy blocks our patients from trying out their possibilities in the workplace, from "flourishing" in this important area due to what is (largely) a misconception of their incapacity to perform because of their disease. In turn, society and the economy as a whole is losing out, as otherwise capable persons are excluded from the workforce.

Preliminary Conclusion

Asking to make a special place for the person with a disease like epilepsy in society seems a simple task at first: why don't we just give them a bit of extra help? Yet those who need assistance, who show us their vulnerability, bring into focus some of our darkest fears: fear of the body, fear of death, and of the uncertainty of our identities in our workplaces. To give a place for the vulnerable person in society means accepting that vulnerability in ourselves. The *uncanny* feeling that the person is somehow like us shows us that we do not have that firm a grasp on our bodies, on our relationships, or on our identities. Our emotions toward these persons are particularly intense and show themselves as fear and disgust. However, the table below does suggest some preliminary solutions to these fears. We seek both individual and institutional support to combat them:

[582] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions.* Cambridge University Press, Cambridge ; New York, p. 135

Table 8: Society's Fear of the PWE

Fear	Proposition of solutions	Reason for proposition
Fear of the body and death	Make epilepsy known (move epilepsy "out of the shadows")	Combat for those most concerned (doctor, patient, family); can be helped by social institutions and workplace trainings
Fear of inadequacy	Government programs to encourage hiring PWE and adapting workplaces	Due to marginalization, individual employees themselves unlikely to change practices

In the highly narrowing expression of fear, there is a tendency to enclose the borders around oneself, to "hide" and "make safe" those things which are scary to us. However this fear, as a highly narrowing emotion, may keep us safe in the moment, but it can also stop us from thriving with others in society. The fluidity and uncertainty of many things in our world today — our work, our relationships, our family life — encourages us to run for hiding. The result, however, is that for someone who is vulnerable, who needs more help in order to flourish (which is all of us), isolation, stigmatization, and marginalization result.

If we no longer openly forbid a certain group of people from the public space, we have found new, hidden ways to do so. The workplace is one of those most damaging spaces for the vulnerable, one in which she finds herself not even allowed to enter, or is quickly dismissed. In turn, the individual suffers not only financially — but only bodily. In the case of Natalie, it made her previously stabilized epilepsy restart.

However, this kind of situation also represents considerable financial costs to society as a whole, in terms of healthcare and non-employment costs. Thus if we cannot convince with the idea of individual flourishing in mind in today's light capitalist societies, we can at least convince with this economic logic in mind. Natalie could have been in stable employment, working in a job for which she was trained. Instead, she is living in a healthcare institution, at considerable cost to taxpayers. Fear that results in disgust, stigma and isolation is simply bad for the economy and for the individuals living in that economy. Thus we cannot only depend on local, individual efforts to combat this marginalization. If it is up to the individuals concerned to change the face of epilepsy by making it ordinary, there is also a need for social structures to allow this change to happen from an institutional level, because at the moment there is a double exclusion taking place: the PWE who is

stigmatized due to her disease, and the PWE who is stigmatized due to her lack of employment. To combat both, we cannot only leave this task up to individual will.

To return to Aristotle's view of epilepsy as an "intermittent bad," we do not endorse Aristotle's view that those who have periodic moments of lack of control are any less virtuous — or teachable — than others. Aristotle's viewpoint only confirms Nussbaum's theory that we are ashamed of our own vulnerability. However, he does raise for us, in line with Nussbaum's philosophy, an important point: these moments of lack of control have been punished since Antiquity, at least partly due to the shame of showing one's vulnerability before others. Given the entrenched nature of this shame, recognizing and ceasing to chastise vulnerability will likely only be stable through institutional change. One of the ways suggested by Bauman is to promote *mixophilia*.[583] We cannot hope to integrate those with epilepsy if we keep them away from society, or make them "pass" in society; we need instead to mix them in society and promote diversity. Thus one of the solutions we propose is government programs to include the PWE in the workplace.

However, once again, we need to be realistic here, not only in light of what Bauman says in terms of the disposability of the labor market today, but also in terms of who or what can we do to reduce fear of society toward the person with epilepsy (and in turn, all those who make the public uneasy with their "disturbing" behavior or need for adaptation in their working environment). Goffman said that there are those "sympathetic others" who share stigma with the person, who are privy to the life of the stigmatized person, seeing them as ordinary.[584] In terms of epilepsy, we can identify at least two key "sympathetic other" relationships, that of the family and that of the healthcare provider. Of course to really change society, what we need is to expand this circle of sympathetic others, to move epilepsy out of the shadows, in order for it to become normal. However, in order for the PWE to be able to solicit their help, we will also need to deal with their fears.

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[583] Bauman, Z., 2007. *Le présent liquide: peurs sociales et obsession sécuritaire*. Seuil, Paris. P. 118.
[584] Goffman, E., 1986. *Stigma: notes on the management of spoiled identity*, 26th pr. ed, A Touchstone Book. Simon & Schuster, New York. p. 30

2.6.3. Fear in the Family

In this section, we will introduce fear in the family and its impact on PWE's flourishing. Fear in the family stems from similar fears that we have already discussed (fear of inadequacy, fear of death), but it becomes more destructive in the family due to the importance of the PWE to the person experiencing that fear. The fears that we will relate in this section are largely the fears as understood by the patients themselves or as told in some form or another by their loved ones. As we have maintained, the experience of fear is both bodily and cognitive. Thus patients have understood the fear of their family member toward them in multiple ways: they witness the family member's emotion in their faces, in their bodies, in the temporalities when they come out of a seizure, when they ask their family member if they can "play outside" or if they can "leave the family nest." However, our patients also evaluate the link between this bodily manifestation of fear and the actions taken by their family members toward them. Thus, as we have maintained, the evaluation of fear is both bodily and cognitive, and the evaluation of that emotion is informed by both.

Before continuing our discussion, let us clarify our focus in this section, given our research limitations as well as our specific research aims. While we were able to interview and capture several family contributions, notably through patient association meetings, it was our ambition to understand how fear affects the PWE, rather than the other way around. Thus this section largely reflects the patient's perspective on these fears emanating from the family. We have not found incoherence between patient narratives and the narratives of family members toward their loved ones, who readily admit that they are "scared" of their family member's epilepsy, and most directly, because of the fear of death of their family member. Some even say that they see "death before their very eyes" when they see a seizure. In future research, the family's perspective will be a fruitful investigation to explore; however, it is beyond the scope of our research for the time being.

To start with an indication of the prevalence of fear for the family, in the medical-social center, 11 out of 19 patients interviewed discussed how fear of their family members toward their epilepsy affected their ability to pursue what they wanted to in life, due to overprotection. Fear emanating from the family thus remains pervasive and cannot be excluded from our discussion.

1. Fear of Death

In Upheavals, Nussbaum describes in detail the grief she felt at the loss of her mother. In reference to this experience, she says, *"there is one reason why there is something terrible about the death of a parent…it is that death that seems the most final and irrevocable, being the death of a part of one's history that has great length and depth, to which no replacement can bear anything like the same relation."*[585] Losing one's child is even more final and irrevocable; it means not being able to look ahead as well as losing one's past. Families with a PWE in the family (and it is often just one person, as epilepsy is rarely genetic), find themselves facing a "sudden fear of death before their eyes"[586]: in the case of parents, not only are they seeing their child's death, but they also seeing their genetic line eliminated. This fear of death is informed by a long-term vision of flourishing through generations. The death of the family member is therefore also a rupture of the possibility for flourishing beyond one's body.

As we have maintained throughout this chapter, the fear of the death for the PWE and for their witness is largely a background fear. In the case of strangers, or those who are said to be replaceable in today's liquid modernity (friends, coworkers, strangers), this fear of death is uncanny and somehow reminds them that they may one day be in a similar situation. However, this fear is much more intense for the family member of the person who has the disease because of their importance to the person concerned. Nussbaum tells us, *"the background fear of death usually includes both the highly personal thought that it is bad for me to die and the general thought that death is a bad thing; so too, the fear of a loved one's death involves fear for that person and also for one's own goals and projects."*[587] The fear of death of a family member is not only a question of fearing death in general, it is also a recognition of the importance of that particular person to our flourishing. Witnessing the person's seizure is likely to be both fearful for those whom we love but it is also has a relationship to ourselves. In the case of parents, this fear extends to the idea of flourishing in the future tense, beyond their own lives, through their children.

Because of these elements, the fear of death in the family member (particularly a parent toward their child) is not only uncanny, it is also more intense, more painful, and

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[585] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 68

[586] This expression was employed by a family member with epilepsy, when explaining why she was scared of the seizure. Informal interview with a family member, Lyon, April 2019.

[587] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 73

more directly related to their individual flourishing. Instead of being a *vague* fear, it is one intensely focused on a *particular* object, specifically on a particular person that is important to us. It is not only a question of witnessing that person's death "before their eyes" but also losing an important part of one's self, of the narrative of the past and of the future, as well as that person's implication in our life projects.

Overprotection

Fear of death leads family members with epilepsy toward a variety of strategies, but the one that has the most impact on the person's flourishing is overprotection.[588] From the word "protection" in its etymology, we can understand this action as one of "covering in front" of danger. Parents or other loved ones[589] "over" cover to protect their loved ones from the risk of death or bodily harm, by helping them to avoid places and situations of risk. However, this fear of death becomes detrimental when it inhibits the capacity for flourishing for the person being protected.[590] It also leads to relationship problems between the two. Let us relate what several patients say about the effect overprotection has had on them.[591] These three stories are stories of adults living at the medical-social center of the Teppe. Sometimes the very reason that they have chosen to live at an institution instead of at home is because of the disastrous effects of overprotection:

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[588] Although overprotection is common in patients with epilepsy, its detrimental effect on epilepsy patients has not been extensively researched although they remain an important part of the healthcare plan in some specialized epilepsy treatment centers, such as the Teppe. See Chapter 3 for more information on the Teppe's solution to this problem. Aydemir, N., Kaya, B., Yıldız, G., Öztura, I., Baklan, B., 2016. *Determinants of felt stigma in epilepsy.* Epilepsy & Behavior 58, p. 76.

[589] It is not to be assumed that this action of overprotection is limited to parents toward their children, nor from non-epileptic toward epileptics. Indeed sometimes knowing more about epilepsy can augment or distort that fear. In one interview, one patient described his overprotective relationship to his girlfriend (who also has epilepsy). He always held her hand, or held her waist, when they were together to make sure she was "protected" when he was with her, in case she had a seizure and could hurt herself. This is an example of "physical" overprotection to prevent harm.

[590] While the idea of "false self" and "true self" as proposed by Winnicot could appeal here to help us unravel this complexity, in most cases epilepsy arises at various stages in childhood (or in adulthood). If we follow Winnicott's theory, we could imagine that the child whose epilepsy developed at a stage after infancy was normally given the opportunity to live an experience of a "true self" during infancy and then they had to become a "false self" in order to adjust to the burden of the disease on them and their family members. Thus this is not really a question of interfering with the child's early development, but rather their later development when they seek to achieve greater degrees of autonomy/independence from their parents that something goes wrong. We therefore will not use Winnicott's analysis here; however, we could extend our analysis, as some theorists have done, beyond this infant-mother relationship to include "holding" as the role for the family member to take instead of overprotection in epilepsy. For more information on Winnicott's theory, see: Winnicott, D.W., 1960. *Ego Distortion in Terms of True and False Self.* In: Winnicott, D.W., Ed., *The Maturational Processes and the Facilitating Environment: Studies in the Theory of Emotional Development.* Karnac Books 140–152.

[591] These narratives are parts of interviews conducted at the medical-social center of the Teppe.

- *"My mother worried too much…she was always hovering around me. Finally, I told her I had had enough. That really hurt her, when I said that, but finally I had to!"*
- *"I prefer to be here because when I'm at my mom's it's terrible…she obviously overprotects me…when I say to my mom, 'I want to go outside with the others,' she always says no, I won't let you outside because you're going to have seizures and I will have to bring you back home' She is always overprotecting me, the disease scares her a lot. So here at the center, I feel more free."*
- *The Teppe (the medical-social center) was an escape route for me…I was so scared to tell my mother that I wanted to go here, because we are so close. It's my mother especially who didn't want to let me go…when I came here, she finally accepted it, but when I arrived, the doctor said that it was on condition that I did not talk to my mother for 4 months…for me, it's was like taking medicine to have done that…coming here was the solution to the problems with my mother!"* (this patient is not a young adult, but a 40-year-old woman)

Overprotection has been researched in psychology, mainly in the parent-child relationship. These studies have shown that overprotective behaviors by parents are an important factor leading to later anxiety disorders in their children.[592] Various models have suggested that overprotective behaviors reinforce the idea for the child that the world is dangerous and encourage avoidance behaviors, as well as limit the child's capacity to develop skills and confidence.[593] In other words, it is as if the person's own fear of their bodies is multiplied by their parent's fear, leading to new learned experiences of fear.

However, there is another aspect in consideration of epilepsy. As the main testimony to the seizure itself, witnesses hold a certain epistemic authority over knowledge of the seizures. Unlike the patient, they have access to what happens during the seizure, how long it lasted, as well as the harm inflicted. The witnesses' fear has authority to the person, not only because of the importance of that person, of their relationship with them, but also because the epistemic importance of their testimony during the seizure. As the witness of a seizure is usually a family member, they are sometimes seen by the PWE — and the doctor — as better judges of the risk than the person herself.[594]

However, this experience of fear easily becomes one which is deformed, twisted, manipulated by both the family member and the PWE, and it leads to concrete actions,

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[592] Clarke, K., Cooper, P., Creswell, C., 2013. *The Parental Overprotection Scale: Associations with child and parental anxiety.* Journal of Affective Disorders 151, p. 618.
[593] *Ibid.*,, p. 619.
[594] In order to give testimony to the frequency of seizures, their duration and severity, family members are often encouraged to participate in the medical consultation with the doctor and the patient.

especially overprotection. This can take multiple forms, but we can see some tendencies from the three stories highlighted above: general anxiety (hovering behaviors to protect the person), but also more extreme measures (forbidding the person from going outside, insisting that they say seated for their safety, not allowing them to engage in certain activities, etc.). When protection becomes *over-protection*, it means replacing the person's capacity for choice with needless restrictions. Overprotection leads to passivity for the person affected, but also reliance on the family member's assistance. This becomes both stressful for the person (who wants to be active, but becomes too afraid or thinks they are incapable of doing so), and for the family member, who must vest considerable time and energy in provision of assistance. This fear is a *boomerang fear*, originating in the family's fear, hitting the person in its path, and coming back in new, dangerous ways to the family member herself. The medical anthropologist Kleinman says that epilepsy follows a *social course*, affecting not only the patient but the family in diverse ways.[595] This fear of death is so destructive, so overwhelming, that it boomerangs back to influence the family member, the patient, but also their relationships to each other, and other family members.[596] The whole family is affected, often in a negative way.

In the stories that patients have related above, it was not even possible to imagine an active path for these patients without both physically and psychologically separating themselves from their parents. In these three stories, their only solution was a medical one, to be integrated into a medical-social center away from their family member's fear. This was the only way in which both parents and their (adult) child could continue flourishing: for the parents, it meant being able to release their fear, as they knew that their child was in "good hands" and for the PWE, it meant the space and time to develop their own capacities, away from their parents.

Kleinman *et al*. also add the interconnection between social stigma and overprotection. These authors propose that due to the social stigma of epilepsy both for

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[595] Kleinman's definition of social course is as follows, "*epilepsy develops in a local context where economic, moral, and social institutional factors powerfully impact the lived experience of seizures, treatment, and their social consequences. The social course of epilepsy, furthermore, is plural, heterogeneous, and changing.*" Kleinman also discusses the social but also the economic burden of epilepsy for patients and families as a whole. While his analysis was confined to China, this finding largely correlates with our research in both France and China (including the considerable importance of the family in lived experiences of epilepsy in both countries). Kleinman, A., Wang, W.Z., Li, S.C., Cheng, X.M., Dai, X.Y., Li, K.T., Kleinman, J., 1995. *The social course of epilepsy: chronic illness as social experience in interior China*. Soc Sci Med 40, p. 1323 and p. 1328.

[596] As in many difficult health situations, the sibling with the health problem is often given more attention by the overprotective parent, leading to problems between the siblings.

patients and their family members, fear of showing epilepsy to others may encourage family members to "sequester their epileptic at home." According to them, *"overprotection of sufferers, a form of intra-familial social control, aimed at preventing epileptic family members from being publicly shamed and from potential physical harm, is not infrequently and not without a sad irony, the chief constraint on patient's life choices."*[597] Thus overprotection is knotted to perceived social stigma of the epileptic person leading their family to isolate the patient, impacting their capacities to develop[598] and act upon their life projects.

The examples we have highlighted above extend from the parent toward the individual child. While this relationship is particularly difficult for the parent, given the instinctual need to "project" their child, there are many examples of other family, friend, and love relationships which are affected by this overprotection. To give a holistic view, we will relate the story of an elderly woman in China, a situation in which we can clearly see the negative effect of overprotection of the son toward his mother. She tells me,

> *"My son is very busy! Also he does not have a big enough apartment for the both of us, so I live alone. However, since my last seizure, when I hurt myself when I fell at the supermarket, he told me he doesn't want me to go outside. So I always stay inside now, other than when I have doctor's appointments. He brings me my groceries so I don't have to go to the supermarket or do other daily tasks outside where I might have a seizure."*

This patient is elderly: she has few social contacts and lost her husband several years ago. While the son's actions may be well-intentioned, his fear of his mother's seizures has resulted in considerable social isolation for his parent. His fear has caused problems not only in terms of the mother's sociability, but also in terms of her treatment. As she loses consciousness during her seizures, and there is no one around to witness them, she cannot relate to her doctor how many seizures she has had. In turn, as the son himself, as her only social contact, is not living with her, he cannot record the frequency of her seizures. This means that no one (the doctor, the patient, the family) is informed about the whether or not the treatment plan is working. In this case, overprotection can also lead to inadequate (or at least uninformed) treatment plans. Overprotection therefore extends

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[597] Kleinman, A., Wang, W.Z., Li, S.C., Cheng, X.M., Dai, X.Y., Li, K.T., Kleinman, J., 1995. *The social course of epilepsy: chronic illness as social experience in interior China.* Soc Sci Med 40, p. 1327.

[598] See Chapter 3 for a discussion on adapted preferences, as highlighted by the capabilities approach, and suggestions to help patients move beyond such adapted preferences and see their possibilities (one solution will be to find strategies to overcome this family overprotection).

beyond the private family cadre and becomes one directly related to the treatment plan and the efficacy of that treatment plan.

2. Fear of Inadequacy

In addition to fear of death, the fear of inadequacy in the patient-family member relationship also blocks the PWE's flourishing, although this emotion is more complex to unravel than in the former sections. In the first place, fear of inadequacy in the family member toward the PWE is a question of being unable to lend assistance. For family members who are surrounded in their daily lives with the PWE, and who cannot necessarily help them, the source of the fear comes from an evaluation of being unable to help the person they love when they see the seizure. Thus fear of inadequacy is related to Bauman's idea of non-performance, but in the sense of being unable to render assistance to the vulnerable person, who is not just a stranger in the street but in their circle of concern. This sometimes leads certain family members to avoid the person with epilepsy. For instance, Melanie said that,

> *"On my father's side, my family has accepted my epilepsy. On my mother's side, they are still scared (of my epilepsy) and that is why we see each other less often. I think it's because of that that they don't accept it. Well, it's not that they don't accept it, it's just that they are scared. They say that they cannot do anything, if something happens."*[599]

It is not just that these family members avoid the person with epilepsy; this fear of inadequacy also has ripple effects on the entire family. Melanie said that not only does she see that side of the family less often, but neither do her parents. Thus we can see just how much this fear invades the lives not only individual patients, but of whole families.

To give practical solutions to this fear of inadequacy, we can propose that since this fear is related to a lack of information, a possible mitigating strategy would be information so that these family members can know. Melanie's extended family members are not really scared of death to the same degree as the mother or family, but they are scared about being unable to lend assistance to a person that they care about. This shows us that those who are in the "circle of concern" to help the PWE are not just the direct family members, such as parents, but the wider family environment, which could benefit from further information to "release the fear" by better understanding the disease. Again this shows that programs such

[599] Interview conducted at the Teppe, March 2018.

as therapeutic patient education are too focused on the patient, rather than their wider circle of relationships. Melanie's story suggests that therapeutic education can benefit not only parents, but also siblings and a wider group of family members, so that fear does not become a destructive force in these relationships.

However, there is another interesting aspect to this fear of inadequacy as expressed by the family member toward their child: acceptation of the family member's limits. As we saw in society's fear, fear of inadequacy is related to certain expectations of individual performance. Thus this fear is also a fear of the other person being inadequate in the family's eyes. The patient, due to their illness, is not able to "perform" as the family member and society expects. We have already seen that in Mei Ling's case how changing to a less prestigious career was highlighted by both the mother and the daughter. For both, the change was disappointing, because she was not able to perform.

Therefore this fear can also be understood in terms of parenting, and the expectations surrounding parents today. If their child is unable to "perform" in today's societies, this may be interpreted by the parent as not having been a good enough parent or that the parents have not provided all the ways and means for their child to flourish. The responsibility for non-performance is often paradoxically on either the parent, or on the child: rather than accepting the uniqueness of each individual, it is expected that that the individual person rises up to society's expectations. This has even pervaded family life, as we have high expectations of our children and of ourselves. This can lead to serious repercussions. Let us better understand this problem through a narrative case study:

<u>Colette's story</u>

Because of her epilepsy, Colette has to wear a helmet to protect her head in case she falls. She has important cognitive difficulties, as well, which make it hard for her to participate in the healthcare consultation. She prefers for her parents and for her doctor to decide the treatment and usually she follows what they tell her. A very important relationship to her is with her parents. As they are the ones who decide the treatment with the doctor, they are also essential to her epilepsy treatment; however, they are also the closest persons in her life. She currently lives at a medical-social center, and it is difficult for her not to see them regularly. When she has holidays, she always looks forward to seeing them, or rather more her father than her mother. She says that she does not always get along with her mother, that she loves much more her father than her mother. This is because her father knows her limits, and does not "force her" to do things which she is incapable of doing. Her father and her mother often argue about this, because her mother thinks she always should be like other children. She always expects Colette to be "normal" and cannot understand why she should be treated differently. Colette says because of this, she feels more comfortable with her father. She even says she loves him more.

When we discussed the patient's fear, we proposed that bodily acceptance could reduce their fear. However, as we can see from Colette's story, for parents or other loved ones, acceptance of their loved ones is equally important. Their acceptance is not only acceptance of their family member's disease; it also includes accepting their family member's limits. While we could just accept that this is a normal expectation of parents, which their children will (inevitably) fail to achieve, in the case of epilepsy, it can become an unnecessary blocking factor and reduce their ability to act. Colette describes how her mother is always pushing her to be like other children. By so doing, her mother is encouraging Colette to do things which she cannot do well, or even do at all. Now at this stage, either the parent blames herself (she must have failed as a parent) or the parents blame their child for not trying hard enough. The result is not only a disappointment from the parent's side, but also from the patient's side, because she was unable to perform *for* her family member. In the next situation, it becomes harder for the patient to try again, to believe herself capable.

Bauman says that the faculty to affront the challenges of life is the *workshop* where self-confidence is made.[600] The parent's fear of inadequacy can have a particularly detrimental impact on the patient in inducing passivity, anxiety, and even creating fear where there was not any before. In the next chapter, we will introduce our family life empowerment approach to give the family prominence, but also limits, in how they can help their loved one to flourish.

[600] Bauman, Z., 2007. *Le présent liquide: peurs sociales et obsession sécuritaire*. Seuil, Paris. p. 88

2.6.4. Fear in the Doctor-Patient Relationship

Having established an enabling relationship for the family, let us turn to an equally essential relationship of the PWE, the relationship with the doctor. Given the considerable fear lived by the patient, coming from incapacity to control her body and the weight of a society that is scared of their disease, the relationship between the doctor and patient can be a privileged relationship. The doctor is the one who knows and understands the disease. As Goffman says, the doctor is that "sympathetic other" [601] that sees epilepsy as ordinary and therefore the patient should not be scared to tell details about epilepsy. This relationship can bring not only sympathy and listening for patients but also solutions to help the patient to live better with her disease. However, this encounter is also a problematic one for patients because it is sometimes a relationship of fear. Given the considerable consequences that such a strong emotion can have on this important relationship, especially for our subject of patient empowerment, it is urgent to investigate this relationship and to try to find solutions. To help understand how the doctor-patient relationship can be one of fear, let us start with a story of fear in this relationship coming from the family's perspective:

<u>A family's story</u>

A family has vibrant, creative, and active boy who is constantly amazing them with his antics and creative games. One day, when he is four years old, he seems to have a stroke: one side of his body is completely immobilized. The parents panic. They do not know what to do and watch their child with growing concern. Thirty seconds later, all of a sudden, he stops having the stroke symptoms and starts playing again. The parents say that "he seemed so normal once he starting playing again that we thought it was a one-time incident." However, several days later, the "stroke" repeats. They decide to call their primary care doctor who sends the patient to the emergency department at the local hospital.

Based upon the symptoms described by the family, the emergency department attending decides to send the boy to have an EEG.[602] *The test shows abnormal seizure activity, indicating that he may have epilepsy. The technician does not hesitate to tell the family his diagnosis: a rare and severe type of childhood epilepsy. The neurologist treating the case*

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[601] Goffman, E., 1986. *Stigma: notes on the management of spoiled identity*, 26th pr. ed., A Touchstone Book. Simon & Schuster, New York. p. 31.

[602] The human electroencephalogram (EEG) has been used to detect epilepsy since 1929. While a convenient and inexpensive way to show abnormal excitabilities in the brain, it has a number of limitations. In particular around 10% of patients with epilepsy have "normal" EEG results, while an abnormal EEG does not necessarily indicate a seizure disorder. Smith, S.J.M., 2005. *EEG in the diagnosis, classification, and management of patients with epilepsy*. Journal of Neurology, Neurosurgery & Psychiatry 76, ii2–ii7.

concurs with the technician's opinion and decides to put the child on heavy doses of antiepileptic drugs. He thinks that it is vital to stop the seizures at all costs, given the important period in the boy's life and the potential of the seizures to affect his childhood development. However, this treatment is completely ineffective: not only do the seizures continue, but the child loses all of his energy. His mother says that he "became like a zombie." He no longer played; he was constantly tired, and he no longer interacted with those around him.

The parents became active immediately, not by desire, but out of fear. They call the neurologist and ask for another appointment. What they notice about this encounter is that the doctor does not look them in the eyes. Not only is he evasive on the diagnosis and the treatment plan, but he refuses to discuss or negotiate with the family other treatment possibilities, other diagnoses, or to consult other neurologists on the case. The family says that after a few of these appointments, they had lost all trust in this doctor. Here was an "expert" who refused to look at them, who did not want to discuss the treatment plan, and worse of all, everyday they were witnessing how their once bright little boy was disappearing. They decide to look for another expertise. Luckily they have a contact with a doctor at a university teaching hospital through family contacts and they are able to secure an appointment quickly.

The relationship with this new neurologist is completely different. She immediately says that she is not certain about the diagnosis. While the patient does seem to correspond to the epileptic syndrome described by the first doctor, she thinks he fits the criteria to about 68%. The minimum for the diagnosis, however, is 70%. She says to the family that she does not really know if this is the right diagnosis, especially as so far, it has not helped the patient. Instead of continuing with the previous doctor's treatment plan, she decides to consult other specialists and communicates the ongoing results of these discussions to the family. All along, she is clear with the family that the diagnosis is uncertain. The patient is an individual case, corresponding to no "known" epilepsy syndrome. The treatment is therefore uncertain and needs to be planned with great care by the doctor, but also with the family and the patient. The doctor needs not only their informed consent, but also their collaboration during this difficult period.

Finally, the treatment was, as in many of cases of this type, a trial and error process of different combinations of medicines. The family, the doctor, and the patient worked together toward a solution: finally they agreed that instead of trying to completely stop the seizures, they would try solutions that were less heavy, but allowed the child to continue being creative and active. The admission of uncertainty by the doctor eased the family's fear. They said that they could finally relax and put confidence in the doctor and become less active in the search for a solution. They decided at one point to let go, to let the doctor decide what was best for the patient.

By this time, three years had passed. The patient was now 7 years old. The neurologist had insisted all along that the patient comes to the doctor's appointments with his parents, despite his young age. After three years, and a less heavy dose of medication, the patient, despite being only being seven, knew his epilepsy and treatment very well. He even became a spokesperson at his school, informing his fellow students about the disease so that they would not be scared. It was that this point that the parents even let the child start seeing the doctor without them in the room.

After a long and difficult period — for the patient, for the doctor, and for the family — the epilepsy was finally stabilized. After not having seizures for a few years, the neurologist even decided to begin to taper him off his anti-epileptic medication. A day came to pass when the neurologist said to her patient, "well, we no longer have to see each other, but come back if you want to."

Both the patient and the doctor had a hard time saying goodbye to each other. For the doctor, this was an example of real collaboration, one which validated her expertise as a professional and need for an interpersonal relationship with her patient. It even had a happy ending, in that she was able to find a way to stabilize his epilepsy. For the patient, this represented an important time in his development, one in which he was learning about himself and about relationships. Epilepsy was a scary event, but it was also one in which he learned about himself and his potential. For both, the collaboration was mutually rewarding.

Today the patient is again happy, creative, and bright. And seizure free.

We will use this narrative to understand the expressions of fear in the relationship between patient/family and the doctor, as well as the solutions that the patient/family went through to mitigate them. However, in the first place, let us contextualize the interview in its time and place. This was the first interview I did as part of my research project, with a family who was willing to tell me a story with a "happy ending," one where they could find the right doctor for their case, and also one in which they were engaged in a real partnership with their doctor. I was recommended to talk to this family by a patient association, because for "once" the patient and the family had found a mutually cooperative relationship with their doctor. What surprised me from this interview, despite its intention to show me best practice in patient-family-doctor partnership, was that it was a situation defined and motivated by fear.

In this patient and family story, we can see several moments of activity but also of passivity, owing to the severity and urgency of this case, but also their evaluation of the doctor's expertise. When they did not trust the doctor, the family sought out any and all information on the case, including visiting multiple specialists. During this time they could be said to have become "empowered," learning actively about the syndrome, consulting various specialists, as well as patient associations, to learn as much as they could about their son's probable epilepsy syndrome. But this was not out of desire: they became empowered out of *fear*. They witnessed the doctor's hiding behaviors through his lack of eye contact and unwillingness to discuss the treatment plan, which made them question his expertise. This was also a case for testimonial injustice, as the healthcare provider did not take into account the family's and patient's experience and need for discussion.

During the period of "treatment experimentation" with the second doctor, the family and the patient participated by helping the doctor to design the treatment plan. This is the ideal described in Biomedical Claim 3, reaching a solution in collaboration with the patient, the healthcare provider, and in this case, the family. It was also a solution that respected the patient's needs (to stay a vibrant, active child) as well as a critical need to get his epilepsy under control to avoid having the disease interfere with his development. However, once the family and the patient had accepted that a "miracle solution" was either not possible or far off, and once the family finally felt comfortable and could trust their doctor, they were able to disengage and to let the doctor take the lead in the treatment plan. They still had the capacity to participate; however, they wanted to take a step back and to let the patient and the doctor decide. They even said they considered this, *"a considerable relief! to be able to stop fighting."*

Stepping back also gave a place for the patient himself to participate in his healthcare plan with the doctor, in spite of his young age. This is the enabling role we are seeking for the family in patient empowerment: the possibility to help the patient when necessary, but to also know when to step away. In this narrative, the patient became empowered in his treatment when it was right for him (both due to the uncertainty of the treatment as well as his young age); however, the doctor and the family facilitated this transformation by including him in the treatment discussions even when he did not actively participate, so as to prepare the possibility for future participation when he desired and was ready. This may be an ideal, even a dream for many patients and family members with epilepsy, to canalize their fear into possible, beneficial actions, and to have their children participate in their treatment. However it is an example showing us how fear can be a useful emotion, when it is not destructive to the family member, but moves us toward solutions. The family's role due to fear was one of *protection*, not *overprotection*: the fear they felt led them to concrete actions to seek other expertise in order to protect their child.

From this story, we can see that fear of the family was motivated by a perceived lack of control. When they could not communicate freely with their service provider, they became scared as they saw considerable risk for their young son. It cannot be said that with their new provider that the treatment plan radically changed: the new neurologist also did not have an easy answer, but she was able to admit uncertainty to the family, allowing them to gain a certain control of the situation. While it may seem counterintuitive that expressing uncertainty would in turn encourage trust, what we can see in this family situation is because of communication and collaboration with the doctor, the family

believed they had enough information to trust that the healthcare provider was acting in the best interests of her patient. As we will see in this section, the healthcare provider cannot hide their fear from the patient; the best means therefore to mitigate this fear may be to admit it. Admitting this uncertainty may not lead to a better treatment plan from the biomedical perspective, but it could help the doctor-family-patient relationship, moving us toward a solution acceptable to the patient.

In this section, we will be interested in this expression of fear in the other, in this case, the fear expressed by the doctor toward the patient and the patient's fear toward the doctor. In line with our general project in this chapter, our intention is not to make a judgment on these emotions, but rather to identify what this might mean for the *eudaimonia* of both parties, to help move us toward practical solutions. Here Bauman's idea of *fear of inadequacy* will help us identify what is threatened in this relationship.

Healthcare Providers' Fears

In international literature, while some studies focus on patient's emotions and how healthcare providers deal with them, healthcare providers' own emotions have received little research attention, as emotions are traditionally considered as unprofessional or taboo.[603] Most of the healthcare professionals interviewed in this project discussed emotions at some point in either the ethnographic or the interview stage. While one professional expressed this as, *"we do not escape emotions in human professional fields,"* it was clear the ambivalent relationship that healthcare providers had to emotions in their professional practice. Emotions were often described as negative, leading professionals away from achieving high levels of performance in their professions, as well as leading to ineffective professional relationships with their colleagues and patients. In return, healthcare providers encouraged their patients to take "reasoned choices" not "emotional ones." They saw a responsibility toward their patients in helping them control these emotions, both to make "reasoned" healthcare decisions, but also to be in better health (as emotions can cause seizures).

Why is there this reticence among healthcare providers to see their own emotions as important? Why are emotions considered as a blockage in their work? One way to

[603] However for a recent study on healthcare provider's emotions, see: Silva, J.V.D., Carvalho, I., 2016. *Physicians Experiencing Intense Emotions While Seeing Their Patients: What Happens?* Perm J 20, 15–229.

understand this paradox may be to solicit Nussbaum's link between vulnerability and shame:

> *"Human beings appear to be the only moral finite beings who wish to transcend their finite. Thus they are the only emotional beings who wish not be emotional, who wish to withhold these acknowledgements of neediness and to design for themselves a life in which these acknowledgements have no place. This means that they frequently learn to reject their own vulnerability and to suppress awareness of the attachments that entail it. We might also say…that they are the only animals for whom neediness is a source of shame, and who take pride in themselves to the extent to which they have allegedly gotten clear of vulnerability."*

From Nussbaum's quotation above, we can understand that healthcare professionals may see their emotions as showing their own vulnerability and neediness. Healthcare professionals thus sought to clearly define their roles and to establish clear rules of conduct to guide their decision making with other professionals and with their patients. In order to show their expertise before both patients and professionals, some healthcare providers thought it necessary to hide or counteract their emotions. What this reticence may show is that professionals are seeking both individual and collective performance in their professional roles. As our careers are increasingly related to our ideas of our flourishing in today's societies, we seek the means of being able to validate ourselves as professionals as a clear means of expressing our flourishing. Fear of not performing, or performing with emotions, was interpreted as non-performance as it exposed the professional as an *emotional* rather than a *professional* worker. The risk of seeking to squash emotions in order to validate our professional competency however might in turn lead to hiding their own vulnerabilities. As Nussbaum has shown, emotions form important parts of our judgements about our world and are related to our values and visions of the world. By ignoring emotions in their healthcare practices, are healthcare professionals ignoring their own vulnerability, leading to burn-out, brown-out, and situations of conflict with their patient?

One area however in which healthcare professionals admitted a certain apprehension or fear was in terms of their relationship with their patients. All doctors clash regularly with the limits of medical knowledge of diseases and their own imperfect knowledge of medicine; thus doubt is never far away in clinical decision making.[604]

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[604] Bateman, S., 2001. *La responsabilité médicale aux frontières de l'activité thérapeutique Le cas de l'assistance médicale à la procréation*, in: *Juger La Vie: Les Choix Médicaux En Matière de Procréation*, Cahiers Libres. La Découverte, Paris. p. 114.

Epilepsy is a chronic disease which challenges the doctor's expertise and authority. It remains for the most part a medical mystery. Most epilepsy treatments are "trial and error," and patients in our interviews described themselves either as "mystery" to their doctor or even worse as a "guinea pig" because of this process to find the right treatment for their individual epilepsy. For the doctor, there is much incertitude in deciding the healthcare plan, based both on the limits of modern medicine and their own expertise. Their competence is put to the test by this difficult work. Admitting this uncertainty to the patient or to other colleagues in turn puts their relationships with them at risk. It is therefore understandable that all of these situations may be a source of fear for the doctor. To use the words of one patient, *"it's the capacity to put oneself under scrutiny, that is not easy…this is about ego, somewhat. But it's also fear to put oneself under scrutiny. Fear."*

The solution proposed by healthcare providers for these fears was to be willing to admit failure to their patients. However, as this fear is tied to healthcare professionals' visions of themselves in their careers, and in turn to their identities, this proposition remains a difficult task for healthcare providers in today's healthcare infrastructures that seek individual performance. As Bauman has shown us, we in turn blame ourselves for these failures because we could not individually perform for the patient, for the family, for the institution, but also for ourselves.[605]

This fear leads to actions: for some, as we have seen in the family case study, it is to hide the uncertainty of the diagnosis or treatment plan from the patient and the family, to hesitate to ask colleagues their opinions, or to ask for necessary clarifications. All of these actions emanating from fear can lead to medical errors, inadequate treatment plans, and the lack of participation for the patient who otherwise might want to participate. This fear however shows us something vital for the healthcare provider: their desire to provide the best care for their patient.

Fear in the Doctor-Patient Relationship

Now we will turn specifically to expressions of fear in the doctor-patient relationship. To start this discussion, let us first compare the different evaluations of fear in the doctor-patient relationship, as related by healthcare providers *toward* their patients, patients *toward* healthcare providers, and both *toward* themselves as either patients or

[605] Ofri says that fear of making medical errors and/or not performing for the patient is a pernicious source of shame for doctors. For more on shame and other emotions experienced by doctors, see: Ofri, D., 2014. *What doctors feel - how emotions affect the practice of medicine*, Beacon Press. ed. Boston.

professionals. The table below summarizes the expressions of fear described by both actors:

Table 9: Fear in the Doctor-Patient Relationship

What is the doctor scared of?		
Doctor contributions	**Patient contributions**	**Actions**
Fear of showing lack of expertise or capacity of assistance to the patient (*idem* for doctor and patient)		Hiding information from the patient
Fear of giving away medical authority (*idem* for doctor and patient)		Hiding information from the patient
Not expressed by doctors	Fear of making the wrong treatment decision, putting the patient at risk	Playing it "safe"; inadequate treatment plans
What is the patient scared of?		
Fear of medical authority (*idem* for doctor and patient)		Hiding information from doctor
Not expressed by doctors	Non-relationship with doctor	Inadequate treatment plans; lack of participation for the patient

We do not propose this table as a cohesive list of fears; they are the fears discussed among patients and doctors during the research period. However, there are a certain number of convergences between the fears experienced by the doctors and their patients. Both patients and doctors say that doctors may be scared of showing their lack of expertise and/or giving away their medical authority. Both doctors and patients say that the patient is scared of medical authority, which makes it difficult for them to openly communicate with their doctor. There is an agreement over the reasons for these fears.

According to patients and doctors, these fears lead to disastrous results, including hiding information from either the patient or the doctor and/or inadequate treatment plans. In order for the patient to have an active role in the doctor-patient relationship, the doctor must be willing to have the patient take an active role: if this relationship is one of fear, it will be difficult for the patient to participate. From the patient's perspective, this fear means that the patient may end up with an inadequate treatment plan; however it is equally problematic for the doctors, as it means that they did not provide their best care to their

patients. This puts into difficulty both their identities – as persons with diseases, as healthcare professionals – and keeps them from flourishing. It is also a case for epistemic injustice as patients had little epistemic contribution to offer during the consultation.

Patients also signaled that doctors may be "fearful" of making the wrong treatment decision, especially with a treatment which is experimental or which can put the patient at risk. For the patient, however, this is unsatisfactory, as it also leads to inadequate treatment plans. Whether or not the treatment plan was the right one for that particular patient is not the issue here; rather the patient interpreted the action of "playing it safe" as an action resulting from fear. We are not suggesting that this means that doctors should necessarily try risky treatments; rather we are remarking that patients see the actions resulting from the emotion of fear as the problem.

If we pay attention to the patient's and doctor's perspectives, we can see that both actors are aware of these fears in the other and of the possible actions resulting from these emotions. We can also see that neither the patient nor the doctor can hide these fears from the other. When patients spoke in either patient groups or in interviews of bad or inadequate relationships with their doctor, they often described physical gests, such as *"he stared at his computer, rather than at me,"* or *"he did not look me in the eyes."* Thus as we have been maintaining throughout this chapter, the bodily expression of emotion in the other is an important means for the witness to evaluate that fear. If we return to the family story, the family identified "fear" in the doctor by his lack of eye contact. This evaluation of fear and actions of hiding was enough for them to seek other forms of expertise. When the new doctor was willing to admit uncertainty (as well as look them in the eyes!), they no longer felt fear.

As this fear cannot be hidden, according to patients and doctors, it also leads to conflictual relationships – but also inadequate treatment plans and the lack of patient participation. The most common action to get away from these fears – should it come from the patient or from the doctor – was hiding. Thus the doctor did not share adequate information from the patient, or did not solicit the patient's perspective; in return the patient did not share information that they would have shared otherwise. These actions of hiding thus have an impact on the treatment plan. They also lead to conflictual relationships between the two.

In addition, experiencing these fears in the doctor-patient relationship, should it be their own fear or the doctor's fear, remains troublesome for the patient. Given the fear already lived by patients due to their disease, and the fear that they live in society, this fear

is particularly troubling to witness in that "sympathetic other" who is there to lend assistance. When the patient sees this fear mirrored back from the doctor, it can lead to new experiences of fear or habituated experiences of fear in an already fearful life.[606] The actions of hiding or isolation can thus be magnified by a fearful doctor-patient relationship. In addition, as already highlighted, the patient can at times be scared of their doctor, and the fear of medical authority and expertise makes it difficult to freely discuss details which could be relevant for the treatment plan. This leads the patient at times to hide important information.

Fear in the doctor-patient relationship thus blocks both actors. However, it also shows us what is important for both persons in this encounter. For the doctor, the fear is linked to their expertise, but also their need to validate this expertise from other colleagues and their patients. For the patient, there is a need to participate in order to have a say in their treatment decisions, but also because their lives are ones filled with many other situations of fear and uncertainty. Actively participating in the doctor-patient relationship may be one means for them to gain control of their disease. These fears are also evaluations of what is at stake: for the patient, their lives with their disease; for the doctor, their professional lives. Thus we maintain that while the fear felt by the doctor is understandable, it might be an erroneous evaluation of what is at stake in this encounter; actions of hiding or avoidance are what must be avoided rather than open discussion with patients. We believe that if the patient and the doctor can enter into a relationship of mutual confidence and respect — one in which they can openly admit the object of their fear — the relationship can become one of trust, rather than one of hiding. This fear in turn does not become destructive, but moves them toward common solutions.

Fear or Apprehension?

It will be necessary before concluding this section to answer an objection coming from the field. When I told one healthcare provider that patients often said that doctors were scared of their patients, he was surprised, even anxious, about the word "fear" to describe relationships with their patients. He corrected the patient vocabulary as not fear but apprehension. He said that healthcare providers sometimes "apprehend" something that

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[606] This is also called *added psychic suffering*. See: Oguz, O., Fourdrignier, M., Jacquemaire, A., Perret, F., FAHRES. *Lutter contre la souffrance psychique sur ajoutée chez les personnes en situation de handicaps rares à composante épilepsie sévère. Quels enseignements de l'approche interpersonnelle sur les récits de vie et leurs moments clés, pour créer de véritables rencontres entre familles et professionnels ?* p. 12.

is going to happen in the relationship with their patient (such as "saying" a bad prognostic to a patient and having to live through their emotional reaction to the event), leading to a certain apprehension. Thus for this healthcare provider, the source of the apprehension was less intense than fear. It was more an overall feeling, related to the uneasiness in how to communicate with difficult patients or in difficult situations.

What can we say about this mistranslation, if we validate the healthcare provider's perspective that what is expressed is not fear, but apprehension? In the first place, we can maintain that fear is an evaluation of the patient toward the healthcare provider. If this is a mistranslation, this means that at least one person in the relationship has misunderstood the other. However, as we took inspiration from Nussbaum's philosophy of emotions, we can also say that even if there is a certain mistranslation by the patient, the evaluation of this fear shows something important which is probably at threat. Thus even if this feeling expressed is apprehension rather than fear, we can still see that the object of the emotion is important for the person concerned. In other words, what we can see from this evaluation of fear is just how important this relationship is to the patient. The patient comes to the healthcare provider waiting for, sometimes miraculous solutions that the doctor cannot give, but she also comes to interact with someone who understands the disease. The fear that the patient lives outside of the consultation room should at least not repeat itself in the patient-doctor relationship. However in order to reduce the patient's suffering, the healthcare provider must stop hiding. We have already seen how important this relationship is to the healthcare provider. Both need this relationship to live well. Thus there is no reason to hide.

Practical Solutions

As we have shown how important this expression of fear to both persons, we now have to question what to with this emotion in the medical encounter. If incertitude causes fear from both sides, Nussbaum would encourage us to recognize this strong emotion, to work with it, rather than against it, to open a space for discussion. Here we have several ideas to propose. First of all, cognitive behavioral therapy[607] is currently used in epilepsy treatment to help patients avoid hiding behaviors, to expose themselves gradually to their fear in order to overcome it. Similar techniques can be used by healthcare providers in

[607] Leeman-Markowski, B.A., Schachter, S.C., 2017. *Cognitive and Behavioral Interventions in Epilepsy*. Curr Neurol Neurosci Rep 17, 42.

medical schools and in healthcare institutions to help healthcare providers to move beyond these fears and toward fear reduction in this relationship. Given that these expressions of fear not only lead to inadequate treatment plans, but also medical errors, this seems an urgent request to make for healthcare institutions today.

We can also recommend training for healthcare providers on emotions and how to work with emotions in their healthcare practice. One way to do this emotional work is through methodologies like Balint groups, in particular groups organized among equals (such as student-to-student led groups, or colleague-to-colleague led groups in hospital services).[608] Although qualitative studies on the outcomes of such groups remain scarce, Torppa et al. have showed that such methodologies open up the space for future medical students to discuss the emotions experienced in relationships with patients and in relation to role as doctors.[609] As these groups give a supportive environment to expose and discuss emotions, future and current healthcare professionals cannot only express these emotions with their equals, but also critically analyze their own practices through the input of others in a safe environment.[610] Such emotional work can also take place in the classroom, to help future medical students work through emotions with the support of their fellow students.[611]

To conclude this section, fear shows us something important about healthcare professionals: it shows that they too are vulnerable. It is time to recognize that healthcare providers also have these emotions, and that these emotions are not a bad thing, but rather show something important to them in their careers. As we saw from our family narrative, encouraging a good relationship with their patients is as important for healthcare professionals to live well as it is to patients. Thus helping healthcare providers will also help the patient, and most importantly for our project, give them the enabling environment to become empowered in the doctor-patient relationship.

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[608] Although groups vary in size and function, they are generally composed of 5-10 healthcare practioners and meet weekly to discuss case files and to reflect on their healthcare practices in a safe environment. The methodology has been used worldwide with variations since Balint first introduced the methodology. It does not necessarily need to be led by a psychoanalyst and variations/adaptations such as student-to-student led groups have worked well internationally

[609] Torppa, M.A., Makkonen, E., Mårtenson, C., Pitkälä, K.H., 2008. *A qualitative analysis of student Balint groups in medical education: Contexts and triggers of case presentations and discussion themes*. Patient Education and Counseling 72, p. 5.

[610] *Ibid.*, p. 5

[611] Such methodologies work well to have future medical students critically reflect on their internship experiences. Modules at University Lyon 1 medical school for instance allow students to discuss with each other difficult experiences such as announcing a diagnosis. This kind of methodology permits future doctors to express the emotions lived during their internships in a safe environment.

2.7. Toward Patient Life Empowerment

Throughout this chapter, we have seen how and why the word fear is so pernicious in the life of our patients. We have maintained that fear is to be taken seriously as it has an important link to what is of value for us to live well with and in spite of disease. While we give prominence to the patient-doctor relationship, we place it alongside rather than in front of other aspects of living well with epilepsy such as living well in society and in the family. If all of the relationships described in this chapter have been subject to fear, it is because they are all tied to the person's flourishing. The patient needs all of these relationships to live well with their disease.

Determining in what ways fear is experienced in different areas of a person's life helped us identify blocking factors, as well as enabled us to propose solutions to mitigate this fears. As we took a relational autonomy approach as proposed in Chapter 1, this means that an important part of our evaluation involves understanding the structural conditions, not just individual personality factors that influence the patient's flourishing. As we have seen, others are either an aid or an impediment due to fear. Even more extraordinarily for this particular condition, fear can cause seizures.[612] Both from a biomedical and social view, therefore, it was urgent to address this particularly tumultuous emotion of fear before imagining what patient empowerment might look like from the patient's perspective.

Nussbaum's theory advocates that emotions can to a certain extent be taught and changed. We believe that by identifying these emotions, it may be possible to reverse them, if we think carefully of how to mitigate them. We have proposed some individual and institutional solutions in this chapter, although many more may be found. What we can take from this chapter, however, is a "hopeful outlook" by understanding that these entrenched fears are not hopeless and can be worked upon to enable a better life for the patient.

This doorway to reflection *with* the emotion of fear, in being attentive to patients when they discuss this subject and why, adds to our previous discussion of why the current definitions of patient empowerment are insufficient. Given that social, family, and healthcare provider fears keeps the person with epilepsy from living well, this means that for patients, a personalized treatment plan is not enough to live well with their disease,

[612] For some patients, any strong emotion (should be fear or happiness) can help trigger seizures. This is because emotions can cause changes in brain activity/excitability.

even if it is the best available means to treat their disease from a biomedical perspective. To live well with epilepsy, it is necessary to also be able to live well *with* and *toward* others in society.[613] However, it is difficult to live well in society when the person is constantly surrounded by fear coming from all directions. This means that the idea of patient empowerment requires a more global view. Therefore we will call it from this point on: *patient life empowerment.*

[613] See Chapter 3 for explanation of this phrase in Nussbaum's capability approach.

Chapter 3

Toward a Patient Life Empowerment Approach

"I'm going to envision my life. I am going to make my own choices."

- A patient at the Teppe

3.1. Introduction

In this chapter, we will seek the epistemic contributions of refractory epilepsy patients at the Teppe to fully develop our approach. In Chapter 2, we have gone part of the way by understanding that patients need the support of family members, society, and their healthcare providers in order to live well with their diseases. We have understood that living poorly in society (due to isolation such as unemployment) or in their families (due to overprotection) has an impact on seizures. Through our method *with* emotions, we have come to see that patients' abilities to flourish with their diseases are closely tied to their relationships to others.

In order to move toward the patient life empowerment approach, we will need to call on the capabilities approach to help us unravel the patient's conceptions of their empowerment. We will need to tie our results from Chapter 2 with the biomedical claims from Chapter 1 to understand how patient's conceptions of empowerment differ from those of healthcare providers and institutions. We will need to understand how patients conceive of being healthy, what roles they are seeking as patients, as well as the result they are seeking in their treatment plan to help us provide the patient's critique to the existing empowerment framework. The capabilities approach, and in particular Martha Nussbaum's central capabilities list, will help us structure this debate to more fully understand what patients are seeking.

In a first introductory section, we will be highlighting two patients' stories. As we have shown in our discussion on narrative cases in Chapter 2, these stories will help provide us the rich contextualization of our subject from the patient's perspective. They will help us situate our stories *with* patients in order to move the discussion beyond the policy maker or the doctor's perspective and to focus on the patient and what is important to them. As we will see, these two patients are different in terms of their healthcare plans, success in finding solutions to treat their epilepsy, as well as their conceptions of the good. However, as we will soon see, they are looking for similar things in their treatment plan and in their lives.

Having understood what interests patients from these two stories, we will continue by introducing our research method, *with* capabilities. Using Nussbaum's capabilities list as an epistemic tool, we will focus specifically on the capabilities of bodily health, practical reason and affiliation to move us toward the patient life empowerment approach.

These are the specific capabilities that patients themselves have signaled as important, and we will develop these capabilities with our patients' epistemic contributions. With these elements in hand, we will then be able to introduce our patient life empowerment approach. We will then argue why the patient life empowerment approach is different to other existing definitions, such as patient activation or empowerment caring, and what implications there are for taking such an approach in public policy.

In this chapter, we will also use our results from Chapter 2 and Chapter 3 to introduce our family life empowerment approach, focused on what families can do to support patients, as well as to move beyond their fear of their family member's disease. We will also have suggestions for healthcare organizations and patient associations which might want to envisage a family life empowerment approach. Nussbaum's capability approach will in particular help us here to understand what role (and limitations) we are seeking from family members to help support the patient.

Our approach is ambitious. It calls for a greater social responsibility in helping patients to flourish. We are therefore proposing not only an epistemological or ethical disposition for the individual patient but a wider political role for all of us as citizens. While our approach has suggestions for society as a whole, we will pay particular attention to the transformative role of healthcare institutions in helping the patient toward their conception of empowerment. However, since this approach might seem a difficult task in today's healthcare infrastructures, we will end this thesis with a case study of how one healthcare institution (the Teppe) has been able to promote the patient life empowerment approach. We will use a reverse engineering approach to unpack the necessary elements which enabled the institution to move toward patient life empowerment. The purpose of this investigation is to show what resources both patients and healthcare providers will need, in particular to ensure that epistemic contributions of patients form a part of the healthcare plan. To start our discussion, let us now proceed with our two patient stories.

3.2. Patient Conceptions of Empowerment

Christophe's Story

My first interview at the Teppe, a medical-social center specialized in severe epilepsies[614], was with Christophe, a 22-year old in the service for one year. Christophe had a bandage above his eye, a reminder of a seizure he had a few days ago, when he had fallen on the head of his dresser. Christophe told me he was working in a wood workshop at the Teppe and that he was head of the production line. After introducing himself as a worker (rather than as a patient), he told me about his epilepsy, which is, *"refractory…which is annoying…I've tried everything."* One treatment that particularly bothered him during his youth was one in which he had to be careful of his weight, which meant weighing the fat and sugar before every meal. This led to social constraints, which, "*was particularly hard, as at junior high school I couldn't even eat with my friends."* This memory led to others: he described to me how his so-called friends used to mock him about his epilepsy.

The narrative of his disease ties the medical and the social. He continues, *"so yes, I saw many neurologists, which just made things worse…after that I saw some psychologists, psychiatrists, all of that…they tried, but they did not manage…so after a while, I only had one wish: to stay at home. It was chaos. I lived very poorly during that time, but there were others there to comfort me. Did you know, in history, they wanted to kill us because they thought we were witches?"* In his narrative, it is not clear why he wanted to stay at home: was it because his friends teased him? Was it because no treatment seemed to work? Did he isolate himself because of his epilepsy or because of other people? This patient has had a hard time managing his disease, but also living in society *with* his disease. He may be sick because of his disease, but he is also sick because of society and how they treat him due to his disease. Everything crisscrosses to create what he calls *"a situation of chaos"* and he finishes at the Teppe, which tries to help him reintegrate into society.

However, in spite of these difficulties, Christophe is thinking about his future thanks to the accompaniment at the Teppe. He says, "*I know I want to work outside, so I'm looking for a place where I can continue working with wood. If it's in a protected*

[614] See the appendix for the definition of severe epilepsy proposed by the establishment.

workplace[615]*, this would not bother me, but I know that I need to take a break between 12 and 2 PM, as I need to rest for at least an hour. As I've finished my personalized project, it seems more likely that I will be placed in a medical home*[616] *and not in a protected workplace because I will need that rest time."* Even though he has decided to stay long-term at the institution, he can continue working in a field which is stimulating for him.

In the meantime, a problem remains: his lack of autonomy in the hospital service. For Christophe, autonomy concretely means the capability to make choices about his daily life, such as taking his medication autonomously as well as making certain decisions in daily life in the hospital service. His conception of an autonomous life is a bit different than what we are used to: he wants to be able to wake up when he wants, to take his medicine on his own, but also to have the freedom to do everyday things such as eating outside when he wants. Even though he lives in an institution, or perhaps because he lives in an institution, Christophe is looking for ways to increase his autonomy. He is waiting with impatience to go to the medical home because, even though, "*he will still be surrounded by the doctor, I will be more free."*

With Christophe, even though we spoke briefly about his epilepsy at the start of the interview, and the difficulties to find an effective treatment, he was more interested in talking about his problems of living with epilepsy in society. His relationship with his doctor was strikingly absent. After having solicited him several times about this subject, he finally revealed that he had a good relationship with a previous doctor, but that now has a doctor he likes less and who does not seem to like him. He was worried about this new relationship, because, *"before with the old one, I could discuss. The new one, we didn't discuss anything, even at the first interview! It blocked me."* Although he spent at least ten minutes telling me about his lack of autonomy in the service, he never once voiced the need to be autonomous in his treatment plan. Christophe was also not interested in talking about adherence to his medication. This subject simply did not interest him: it was too obvious that he had to take his medicine as prescribed to see if it was effective. However, even if he was ready to follow the treatment advice, that did not mean he was passive. He was seeking autonomy in the timing and in taking of his medication, as this had an impact on planning his free time.

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[615] He is referring to the ESAT (Établissement et Service d'Aide pour le Travail), which is the solution for many patients at the Teppe who are considered apt to work.
[616] FAM (Foyer d'Accueil Médicalisé). There are two of these at the Teppe.

When I asked him his definition of patient empowerment, he said, *"well for me, I have really helped. I had an operation for a new device*[617]*, there are only three* (patients) *who have been able to get it…when they turned it on, I said to myself, I thought in my head, I advanced for myself, but I also advanced for others later. We are stimulated and at the same time, we advance the future of epilepsy, especially for doctors…we help others, in order to help ourselves, but for others especially."*

Unfortunately, the interview was not able to continue on this interesting point, as Christophe started to have a seizure. He raised his hand up high and started tilting to the side. In the time that I could call the nurses to help, he had almost fallen on his head. A patient rushed into the room and put a cushion on his head while three personnel tried to get him to come out of the seizure. He started to come back slowly, but even so, the seizure had lasted more than three minutes, a sign that the seizure was serious, and that he might have a long recovery time ahead of him. "*The interview is over!"* a nurse said to me, laughing, and helped the patient to his room. A few minutes before, we were talking about his life, his work, his relationships with others. All had to stop when he had a seizure. Christophe explained to me that coming out of a seizure meant, *"coming back to myself"* and returning to an active life.

The definition of patient empowerment identified by Christophe is quite unlike the definitions we have seen elaborated in the first chapter. Here is a patient who is eternally in the treatment experimentation phase, who has tried nearly every pharmaceutical and technical solution. He knows his treatments; he understands he needs to adhere to see if they are effective. According to the biomedical claims identified in the previous chapter, patient empowerment has been achieved. However, he does not understand patient empowerment in this way. He sees cooperation with his doctor as a way to help others, both doctors and future patients. In other words, he sees empowerment in relational terms. As we saw in Chapter 1 (Biomedical Claim 2), there was a doubt that doctors saw the benefit of patient empowerment to help doctors to provide better care. Here we have an answer via the patient, showing us how an empowered patient is helping the doctor (with his research), and for future care plans for other patients. By trying out new treatments, by

[617] The patient is referring to vagus nerve stimulation (VNS), a technique to reduce seizures for refractory epilepsy cases. According to Guberman, VNS is not fully understood, but is thought function *interictally* (between seizures), producing long-term alterations in the brain and decreasing seizure frequency. See: Guberman, A., 2004. *Vagus nerve stimulation in the treatment of epilepsy*. Canadian Medical Association Journal 171.

being the "test case," he is advancing the future of epilepsy. However, the worrying aspect to his definition is that he appears to have given up on his own treatment, as he does not see it as a way to help himself.

However, this passive description completely transforms when he talks about his life projects: he talks in an active way, with enthusiasm, about his employment in the wood workshop, about his friends in the service, about his trials and errors of trying to help himself and his fellow patients get more autonomy in the hospital service. It is in this way that he describes himself as an agent: in deciding, planning, and envisaging his life projects. It is evident that Christophe has difficulties, both in his life and in his treatment: his unpredictable seizures keep him from working, neither the doctor nor the patient can find effective solutions to stabilize his epilepsy, and he has a problematic relationship with his current doctor. Could this be that Christophe sees patient empowerment in this way because of the impossibility to find a solution for his epilepsy? Or is it because of a conflictual relationship with his current healthcare provider?

As these uncertainties make it difficult to fully understand patient empowerment from his perspective, let us finish this introductory section by asking one more patient at the Teppe to share her experience. Melanie has quite a different situation from Christophe: she is a success case in the biomedical sense, as she is now stabilized. She describes a very good relationship with her doctor with whom she is able to participate in planning the treatment. You will remember Melanie, as she is the patient that talked about being a "guinea pig" in Chapter 1. Now let us complete her story.

Melanie's Story

Melanie is a young woman with a lot of energy. She laughs many times during the interview and speaks with candor, even when talking about difficulties with her family, with her epilepsy, and the long time she has spent in various institutions. She says that her epilepsy started when she was two years old due to an emotional shock. As with Christophe, she also "did" other epileptic centers in her adolescence[618] and came to the Teppe when she became an adult.

This young woman takes her epilepsy very seriously. She said that in her former center, one of her friends died as a result of a seizure. She says, "*epilepsy is not without consequences…frankly I don't laugh about epilepsy. It's a bit sensitive for me, but it's OK, I manage…"* She says that since she's been at the Teppe, she's doing "quite well" because she found a boyfriend and she is also planning her future. She is also planning a training in administration. She says, *"I will see in function of what I can do!"*

Ten minutes into the interview, and she has still not talked to me about her healthcare plan, just like Christophe. I was therefore obliged to ask her directly. She responds by showing medical and experiential knowledge of her epilepsy and of her medication. She even has come to understand that for her, *"there are two factors* (which cause my seizures)*…the fact of my disease, and if I'm not doing well in my head."* Since arriving at the Teppe, she has been able to work on these emotional factors and now has few seizures. She even says that her epilepsy has stabilized, *"for the time being"* because of this knowledge.

She continues by discussing the last seizure she had, when she was at home: *"that time it was a partial seizure. I'm very diversified in seizures (laugh) I seem to be fascinating. That's why I have the impression of being a guinea pig! (laugh) I am a mystery for the doctors, you see, because they don't know what to give me as treatment so that it will work! So they say to me, 'well, we're going to try that! Let's cross our fingers!'"* Her complex case, the uncertainty expressed by the doctors, seems to have given her the confidence to participate in decisions about her care. She says, *"yes, the doctor, he listens to me. Actually he makes me a proposition, he asks me if he can lower the dosage of one of my medicines, either putting it in the evening, or putting it both the evening and the morning…and to reduce it progressively. I told him, 'progressively, you lower it, but you don't put it all in the evening because for my organization, it will not be easy.'"*

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[618] The so-called IMEs in French, medical-educational institutions for up to 18 year olds.

She follows this explanation with her definition of being empowered, *"for me I think it means that they make me propositions, and I, following those propositions, either I say, 'no, let's eliminate that,' or I just let them decide and generally in that case, it's my parents who decide. When there is a thing that I don't understand and it's important, I ask…after I take some time for myself and I decide."* She sees the healthcare relationship as one of mutual decision-making, between herself, her family, and her doctors. While she says she has the possibility to "have her say" in deciding her treatment, she stresses the importance of others (her family, her doctor) in helping her make these decisions. At one point in the interview, impressed with her comprehensive knowledge of her epilepsy and her treatment, I told her she seemed to have enough information to make her own choices about her treatment. She responded by telling me that was not the point. She said that both her doctor and her family help her to make those decisions and she *cannot* and *does not want* to make them on her own.

In patient empowerment terms according to the biomedical model, Melanie is the ideal that economists and healthcare institutions have been seeking: she gives her opinion to the doctor, she participates in deciding the treatment plan, and she has learned effective strategies to live with her disease. All of these factors have led her to stabilize her epilepsy. However, we cannot call her relationship with her doctor a true partnership. The doctor, with his technical knowledge, proposes a solution and tries to convince her. In return, Melanie weighs the for and against in the context of her life, and decides with the help of the doctor's and family member's advice. She is empowered in the sense that she appropriates the decision as her own choice, but the space for decision-making amounts to informed consent with some leeway for negotiations on the timing of the treatment plan. Melanie, however, does become the main decision maker when she leaves the doctor's office, when she finds ways to live with her disease on her own terms. It seems that for Melanie, empowerment is tied to *gaining control* of her life.

Melanie and Christophe's Conceptions of Empowerment

These two patient narratives already show us some entry-points to understand what it is for patients to be empowered. These two people are not actors by themselves. Both patients have shown us that living with epilepsy means living vulnerable, unpredictable, and difficult lives, which are knotted with others: doctor, families, friends, society, which can help but also make the other person suffer, and even more extraordinarily, make their epilepsy worse. We saw how detrimental family members' and society's fears was to our patients' flourishing. Melanie for instance contrasted the suffering she experiences in society with the welcoming environment she receives at the Teppe. She says that at the Teppe they do not "judge" her, and she even describes her relationship with her doctor as "wonderful" because of this. However, when she speaks of society and her family, she says, *"the disease, I have accepted it! The disease! But the thing I don't accept, is that they don't accept me as a I am…there is in my family, people who are scared of my disease. On my mother's side, there are still people who are scared and that's why we see each other less often."* As with Christophe, Melanie suffers the fear of society, adding weight to her own fears, and likely making her epilepsy worse given that her seizures are tied to strong emotions (the last seizure she had for instance was when she was at her parent's house, not at the Teppe). For both of these patients, having a disease means living with the disease *in* society and trying to flourish *in* society in spite of the disease; to be empowered means being empowered in their lives, *with* and *toward* others. What interests most these young people are their opportunities: the possibility of deciding their life, of staying active, in their workplaces, in their leisure activities, and in having satisfying relationships with others. They are, of course, interested in managing their seizures, but it's not "just" to get them to stop. They want them to stop because having seizures means being stopped from leading an active life. In other words, what interests these young people are seeing what they are capable of *being* and *doing* in their lives.

The capabilities approach of Martha Nussbaum is going to help us to better understand these patients, in their desires and in their limitations to be empowered. With the help of the capabilities approach, and the expertise of the patients at the Teppe, in this final chapter, we will propose the patient's view of patient empowerment — the life empowered patient (*le patient acteur de sa vie*) — and its implications for our institutions.

3.3. An Approach *With* Capabilities

Having introduced how these two patients see empowerment, we will now move forward with our patient life empowerment approach. In this section, we will detail our use of Martha Nussbaum's capability approach (CA). While there are many proposals for the capabilities approach, Martha Nussbaum's particular approach will help us with our subject for a number of reasons.

In the first place, the capabilities approach is an approach to social justice, advocating for a certain number of capabilities to be met in order for the person to be able to live with dignity. Framing the capabilities in terms of social justice harmonizes with the aims of the empowerment movement, as well as our particular project aimed at giving epistemic justice to patients.[619] Secondly, she proposes a list of capabilities that can be used as a basis for constitutional law to move toward what she calls a "partial theory of justice." Proposing such a list as a basis for our institutions and laws inspires us in how to take our approach beyond theory and into the field, to help us understand how to make the patient life empowerment approach a feasible goal for public policy.

Thirdly, Nussbaum's particular approach seeks to include a wider cadre of persons into the framework of justice, which aligns with our goal of envisaging an approach available to all types of patients, including the most disabled. Finally, Nussbaum's clear distinction between the individual and the family in her capabilities approach helped us envisage possibilities – but also limitations – on our family life empowerment approach.

However, we will not be seeking to either defend Nussbaum's list, or to add a capability to her already cohesive (and controversial) list. Instead we will use her list as an *epistemic tool* in order to help us focus on what is important for patients in their conceptions of patient empowerment. In line with Miranda Fricker's epistemic injustice approach, what we are seeking is a method allowing patients an *epistemic contribution*[620] in development of the patient empowerment approach. The capabilities approach has shown such a method. As a first step, therefore, we will give a description of the CA, including the readings selected, before clarifying how we have used the approach as an epistemic tool.

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[619] Fricker has even proposed adding epistemic contribution to Nussbaum's capabilities list. See: Fricker, M. *"Epistemic Contribution as a Central Human Capability."* In Hull, G., 2017. *Equal society - essays on equality in theory and practice*.
[620] *Ibid*. p. 74.

3.3.1. Selected Works

Given the considerable interdisciplinary theoretical contributions and applications of the capabilities approach, for consistency we will be limiting our reading specifically to Martha Nussbaum's contributions. However, we will need to make a further demarcation among Nussbaum's works as her theorizations and inspiration for the approach have developed in time. Nussbaum herself has acknowledged that her overall thinking has undergone change, notably with her endorsement of a Rawlsian type of political liberalism from 1994, which helped her conceive of the political role[621] for the capabilities list we will discuss here.[622] However, several theorists[623] have demarcated these periods for more specific clarity. For our purposes, we will use Eggert's[624] demarcation of two main periods of her thought, as it makes a clear border between her study of the Classics and her later more politically engaged work. The demarcation proposed by Eggert is as follows:

- A first phase of her thought, lasting until early 1990s, marking Nussbaum's grounding in the classics, owing to her study of Aristotle and her ground-breaking work on luck and ethics.[625] In this first period, she made important philosophical contributions to conceptions of vulnerability and fragility.

- A second phase, up until the present, which focuses on exploration of questions of ethics and justice. This research led her to participate in philosophical reflection with a wider social agenda.[626] It was during this period that she conceptualized her

[621] Although her approach has changed in time, there is coherence among her earlier and later writings on this point. Her ideas of a political role for the capabilities approach first stem from her study of Aristotle's role for politics. In one of her first articles on the capabilities approach, she seeks to understand how Aristotle conceived of politics as way to design society permitting *every* member of the group to live well, a stance that her later conceptualisations also endorse. See: Nussbaum, M.C., 1987. *Nature, Function, and Capabilities: Aristotle on Political Distribution.* Wider Working Papers. World Institute for Development Economics Research of the United Nations University 1–54.p. 16.

[622] Nussbaum, M.C., 2000. *Aristotle, Politics, and Human Capabilities: A Response to Antony, Arneson, Charlesworth, and Mulgan.* Ethics 111, p. 102.

[623] Harpham, G.G., 2002. *The Hunger of Martha Nussbaum.* Representations 77, p. 54 ; and Eggert, N., 2013. *Enjeux éthiques des nouvelles technologies de la reproduction: une conception de la justice à l'interface de l'éthique du "care" et de l'approche des "capabilités."* p. 212.

[624] Eggert, N., 2013. *Enjeux éthiques des nouvelles technologies de la reproduction: une conception de la justice à l'interface de l'éthique du "care" et de l'approche des "capabilités."* p. 212.

[625] Nussbaum, M.C., 2001. *The fragility of goodness: luck and ethics in Greek tragedy and philosophy*, Rev. ed. ed. Cambridge University Press, Cambridge, U.K. ; New York.

[626] Her entry into work with a wider social agenda in the capabilities approach was through her work on quality of life issues at the World Institute of Development Economics Research (WIDER) and the United Nations Development Programme (UNDP) in coordination with the economist Amartya Sen, as well as her fieldwork in India.

version of the capabilities approach. In these explorations, her anthropological fieldwork in India and Finland and her readings from other disciplines have nourished the development of her philosophical theories and the potential applications of her theories to society's problems.

We will focus on Nussbaum's explorations in her second period, in particular her philosophical reflection with a social agenda, as this is the period in which her capabilities approach was developed. The advantage of Eggert's demarcation is that it makes clear the different audiences for which her work is intended: if in the first phase, she was seeking to advance Aristotelian ideas of ethics and vulnerability, and engaging primarily in discussions with philosophers, in the second phase, she clearly seeks to engage both philosophers and her fellow citizens in resolving society's problems. It was in this second period that she increasingly started to focus on current political problems in discussion with leading theorists such as Amartya Sen, which led to her collaboration on the capabilities approach.

However, we will also need to limit our readings of the CA in order to maintain consistency as her additions have grown and changed. According to Nussbaum,

> *"My strategy has been to publish versions of my capabilities view as records of works in progress, in order to elicit what I have very often received, criticism that would help me make my view better. Only in Women and Human Development (WHD), published in the spring of 2000, have I made any attempt to synthesize the approach and provide an overview of it, together with at least some justification of its philosophical justification. And even that overview is far from complete. It will need to be supplemented by years of further work, culminating, I hope, in a much fuller and more complete version of my view."*[627]

In our discussion, we will therefore limit our reading to the books that most thoroughly explain her contribution to the capability approach: "*Creating Capabilities: The Human Development Approach"* (2011) and *"Women and Human Development: The Capabilities Approach" (2000),* as well as reference several articles that defend or explain how her approach has developed in time.[628] Her 2000/2011 books are similar, although *Creating Capabilities* is more intended for a general audience and *Women and Human*

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[627] Nussbaum, M.C., 2000. *Aristotle, Politics, and Human Capabilities: A Response to Antony, Arneson, Charlesworth, and Mulgan.* Ethics 111, p. 103.

[628] Notably: Nussbaum, M.C., 2000. A*ristotle, Politics, and Human Capabilities: A Response to Antony, Arneson, Charlesworth, and Mulgan*. Ethics 111, 102–140 and Nussbaum, M.C., 1987. *Nature, Function, and Capabilities: Aristotle on Political Distribution.* Wider Working Papers. World Institute for Development Economics Research of the United Nations University. p. 1–54.

Development can be called a book in transition as it remains among the first attempts to put down her version of the capabilities approach. In our discussion, we will also refer to her book *Frontiers of Justice: Disability, Nationality, Species Membership (2006),* as this book advocates for extending fundamental entitlements to disabled persons. This is important for our project, as we seek to understand what accommodations could be needed for persons who might need significant support, such as patients with refractory epilepsy.

3.3.2. Nussbaum's Capability Approach

Let us now detail Nussbaum's version of the capabilities approach and its potential use for today's societies. The capabilities approach, initiated by economist Amartya Sen, is a goods based approach to social justice: it seeks to inquire into the plural conceptions of the good and well-being. What is assessed is the individual person's real opportunities *to be* and *to do* (their capabilities). The approach provides a criticism to utilitarian approaches of well-being, which aggregates well-being on a large scale, but also to John Rawls's political liberalism, which seeks neither to define the good nor try to produce it. The capabilities approach instead recognizes the plural components of the good and seeks to obtain them for individual persons. In the capabilities approach, failure to secure these entitlements for citizens is a question of injustice, since these entitlements are needed for a life worthy of human dignity.[629]

Martha Nussbaum furthered the capabilities approach by conceptualizing the approach for philosophy, but she also sought to propose several avenues to help make the capabilities approach feasible in today's institutions. Her contribution to the approach in this vein primarily consists in two ideas: she proposes: 1) a threshold of capabilities to achieve what she calls a "partial theory of justice"[630] 2) and a fairly open list of central capabilities for governments to work with to achieve this threshold.[631] With her idea of threshold, she claims that the capabilities approach proposes a partial vision of justice (the

[629] Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. p. 155.
[630] Nussbaum, M.C. *Creating capabilities the human development approach*, New Delhi, Orient Blackswan, 2011. p. 71
[631] *Ibid.*, p. 13

threshold to reach) to assure a minimum of life with dignity.[632] She seeks to defend the capabilities approach as achievable in our current political and economic systems; thus we are here moving from Rawls' ideal theory of justice as fairness[633] into an approach being advocated for within today's societies and systems. Nussbaum has provided the content (the plural list of capabilities) which governments can work with to formulate policy directions.

Nussbaum's version of the approach has a clear political objective in mind. This political aim is both potentially a barrier but also potentially an opportunity for our project. As we have shown in our discussion in Chapter 1, patient empowerment discussions in the political sphere have fallen under the prism of cost reduction measures by making the patient responsible for adherence. Therefore advocating for use of the capabilities approach may become distorted – or in the very least – confused – when advocating for these political priorities. However, Nussbaum's ethical and political project, is as we will see, demanding, requiring us to displace these primarily economic concerns and focus on the individual's opportunities. In Nussbaum's approach, economic productivity is necessary, even good, but it is not the end goal of social life.[634] Therefore her approach already helps us make this transition in public policy discourse from privileging economic cost savings to favoring the individual's opportunities. We will however address the challenges that the capabilities approach presents to us as a political project further along in this chapter.

Like Nussbaum's approach, our own project is both political and ethical: we are seeking political change to help patients live better with their diseases through diverse measures both inside and outside healthcare institutions, and we are arguing that we as a society have an ethical responsibility to help patients become empowered. We have shown that patients are subject to epistemic injustice and that this must be corrected. This epistemic justice cannot only be ensured via individual will or local initiatives. Instead we are looking to ensure a larger political will to make this approach a possible reality. We have gone further than Nussbaum in our approach by arguing that there are potential cost savings to be made should we take a more global view to empowerment. In this way, we are not only asking for such a priority to be put to the forefront (due to our ethical claims)

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[632] She defends the use of the word dignity because she believes that focusing on dignity will help us move toward policy choices that protect and support agency. In our discussion, we will focus on how the capabilities approach favors agency, especially as it is close to our ideas of empowerment. *Ibid.*, p. 30.
[633] Rawls, J., 1997. *A theory of justice*, 22. print. ed. Cambridge, Mass. Harvard Univ. Press. p. 13.
[634] Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. p. 160.

but also that they may provide a new lens from an economic perspective (thus giving us more chance of arguing for such an approach in political discourse given the economic realities of healthcare today). Let us now review the specific components of Nussbaum's approach and discuss why the capabilities approach may help us move beyond existing patient empowerment approaches.

A Focus on the Individual

In the capabilities approach, the level of analysis is the *individual person.* This is justified by Nussbaum based upon the idea of treating each person as an end.[635] In line with Rawls, Kant, and neo-Aristotelian views[636], Nussbaum says that each person possesses an inviolability founded on justice. Therefore, every person should be respected as an equal and as an end, not just as a means to an end, by which she means that people are sources of agency and worth in their own right.[637] According to Nussbaum, *"the person, not the group, is the primary subject of political justice, and policies that improve the lot of a group are to be rejected unless they deliver the central capabilities to each and every person*."[638] Therefore, in the CA, the political and ethical goal is to build this agency (capability) in individuals. In Nussbaum's theory, achieving a life *with* human dignity will be the priority.[639] However the approach does not assume that our functionings and capabilities are independent of our concern for others, or that our actions somehow exist in a vacuum.[640] As we will see, the full role of reciprocity in developing and using our capabilities will be finally taken into account.[641]

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[635] Nussbaum, M.C., 2011, *Creating capabilities the human development approach*, New Delhi, Orient Blackswan, 2011. p. 18

[636] According to Nussbaum, neo-Aristotelians such as herself hold the separateness of persons to be a basic fact, in that persons should be treated as an end, not as a mere instrument for the needs of others. Nussbaum, M.C., 2000. *Aristotle, Politics, and Human Capabilities: A Response to Antony, Arneson, Charlesworth, and Mulgan*. Ethics 111, p. 106.

[637] Nussbaum, M.C., 2011, *Creating capabilities the human development approach*, New Delhi, Orient Blackswan, 2011. p. 18

[638] Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. The Belknap Press of Harvard University Press, Cambridge, Massachusetts London, England, p. 216.

[639] *Ibid.*, p. 162.

[640] Robeyns, I., 2003. *Sen's Capability Approach and Gender Inequality: Selecting Relevant Capabilities*. Feminist Economics 9, p. 65.

[641] Notably in contrast to Rawls, Nussbaum argues that the individual (and not the family unit) becomes the unit of analysis. This however, does not mean that families do not have a vital role to help individuals develop and use their capabilities. As we have already seen in Chapter 2, families can hinder the patient's ability to live well with their disease. They are thus of our particular concern and will need to be input into our patient life empowerment framework to ensure that their role is one of support.

Freedom of Choice

Theorists advocate the capabilities approach as a liberal approach to justice, because it recognizes significant differences among peoples and their right to decide what is the good life. Because the approach focuses on stimulating the conditions for *individual choice*, it leaves open how people will choose to order and use their capabilities. Central to the approach is the distinction between capabilities and functioning: that is, we seek to create the conditions in our societies for people *to be* and *to do* on an individual level (the capabilities) but not their choice of what to do with these capabilities (functioning).[642] As we have advocated in Chapter 1 of this thesis, current patient empowerment programming has focused on ensuring that individual patients make certain choices, which are good from the biomedical perspective; here we see a strong position advocating that it is for the individual to decide what these choices are.

However, in her approach, Nussbaum is not saying that any choice should be justified. She uses Aristotle's conception of *eudaimonia* to show that the freedom of choice which should be prioritized are those *beings* and *doings* which contribute to human flourishing, rather than focusing on an all-purpose social good or "fetishizing freedom"[643] just for freedom's sake. Under this formulation, some freedoms are important while others are not.[644] While the person to define their *flourishing* is arguably, the person herself, Nussbaum allows for a certain amount of government intervention to define what flourishing could be through her capabilities list. Whether or not this leap from individual to a state level can be justified will be discussed in a later section.

Plural Values

Thirdly, in Nussbaum's conception, she uses and defends the idea of plural values[645] to emphasize that the important parts of life are both multiple and qualitatively

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[642] Nussbaum mainly focuses on freedom of choice in the use of capabilities, but with some exceptions, such as compulsory schooling to allow capabilities to be developed.

[643] Nussbaum uses the words, *"fetishize freedom as an all-purpose social good*." Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. The Belknap Press of Harvard University Press, Cambridge, Massachusetts London, England. p. 216.

[644] In other words, those capabilities that do not contribute to human flourishing such as finding a way to pay less tax for the wealthy, as well as those that can be harmful to others, such as workplace harassment.

[645] Nussbaum, M.C., 2011, *Creating capabilities the human development approach*, New Delhi, Orient Blackswan, 2011. p.18

distinct.[646] According to Nussbaum, each person should have the possibility to form their own conception of the good and to engage in critical reflection to *design* and *make* their lives. What this idea of plural values implies is that the choice is for the individual to make, and it is up to individual institutions and other peoples to respect the individual's diverse values. Nussbaum advocates that people will broadly agree to these types of entitlements for others, as it will in turn guarantee their own entitlements to decide and act upon their ideas of the good life.

Social Justice

Nussbaum maintains that even though the capabilities approach started from the development field, it applies to all political and economic systems who desire this type of society, as, "*all nations contain struggles for lives worthy of human dignity, and all contain struggles for equality and justice.*"[647] Because she is concerned with social justice, she sees the level of the nation as the surest way to guarantee that capabilities are sustainable in institutions. She even recommends that they be written into constitutions, given the possibility of constitutions to become part of the vision and the identity of the people. Her approach envisages human beings cooperating for a range of motives, not just mutual advantage, such as love of justice and compassion.[648] This is because, following Aristotle, she believes that humans are social animals seeking goods that are social in nature and that share complex ends with others at many levels.[649]

In the CA, capability failures are those which make space for only certain citizens to profit from governmental institutions as a result of discrimination and/or marginalization. Following Aristotle, she maintains that capabilities are not automatically open to everyone and must be created for them by material and social conditions.[650] The capability approach is therefore an interesting approach to understand why acquiring capabilities is not sufficient. As we can now understand, Nussbaum has similar aims to Miranda Fricker's epistemic injustice approach, in that both seek to secure possibilities to

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[646] For instance, as Nussbaum says, we cannot put health and education into the same metric without distortion, as each capability is distinctly important to the person's *eudaimonia*. *Ibid.*, p. 18.
[647] *Ibid.*, p. 16
[648] As Nussbaum says, "*the good of others is not just a constraint on this person's pursuit of good; it is part of her good.*" Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed, The Tanner lectures on human values. p. 156.
[649] *Ibid.*, p. 158.
[650] Nussbaum, M.C., 1987. *Nature, Function, and Capabilities: Aristotle on Political Distribution*. Wider Working Papers. World Institute for Development Economics Research of the United Nations University. p. 50.

use capabilities in real life contexts to overcome the sequelea of discrimination. The individual level of analysis therefore remains necessary to understand whether or not persons are actually able to put into action capabilities in their environments. In Nussbaum's concept, a distorted vision of capabilities[651] (due to discrimination and marginalization) also becomes a problem in policy development. This means that governments cannot just create capabilities, they also need to create the means for citizens to use their capabilities in practice, as well as help people see that they are capable.

Following this idea, Nussbaum makes the distinction among the capabilities which are *innate* (basic capabilities), those which can be *developed* (internal capabilities) and finally those who are *combined* (combined capabilities), by which she means the capabilities plus the social, political, and economic conditions which allow a space to use these capabilities. According to Nussbaum, the combined capabilities show that support to develop capabilities will be a lost endeavor unless the social, political, and economic environment allows individuals to be able to translate capabilities into functionings. In other words, it is not enough to create laws, individuals must also be able to translate their capabilities into actions on the ground. The capabilities approach is thus demanding, in requiring not only that we give individuals opportunity, but also that they are able to use them in their social environments. In reference to our subject, therefore, we cannot just give patients the right to be empowered through legislation (as many countries have so far accomplished); these rights remain theoretical until they can be mobilized on the ground. The capabilities approach therefore helps us understand that the *facilitating environment* is necessary to help with their opportunities.

Persons with Disabilities

In *Frontiers of Justice*, Nussbaum argues that the entitlements required by the capabilities approach include each and every person in a society. In so doing, she extends her theory of justice to persons with severe disabilities or other impediments.[652] She argues that some persons need more help than others to reach the threshold level of capabilities.[653] For some people, developing capabilities will take more work than others, and some may

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[651] In other words, the difference between people's perceptions of what they can actually be and do, versus what they think they are able to be and to do.

[652] Unlike for instance Rawls, that does not include these persons in his theory of justice, and looks to include them after the overlapping consensus has been agreed.

[653] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 150

never fully be fully capable. Nussbaum, however, defends supporting capabilities for each and every person, a critique to the idea of mutual advantage.[654]

There are two aspects of importance here to our project: one the one hand, she argues that it is for societies to respect the dignity of people with severe disabilities, and tasks governments to develop their human potential, whether or not this will ultimately "create jobs" or be advantageous to society in some other form. Secondly, she argues that persons with disability are as much a benefit to society as they are a cost; by enabling what Bauman has called *mixophilia,* society as a whole benefits from this diversity. She is therefore proposing that persons who are ultimately "costly" to society (in economic terms) are in fact giving back in other ways.[655] We have argued for this idea already in Chapter 2 in relation to the damage caused by excluding PWE from the workplace (although we believe it can be justified both from a *mixophilia* standpoint as well as from an economic standpoint). In this chapter, we will take on Nussbaum's idea and see how patients engage in reciprocity toward other patients to help them to live better with their diseases.

Individual Choice and Vulnerability

A pillar of Martha Nussbaum's overall work remains her focus on vulnerability. The theme of vulnerability is the common link in Nussbaum's at times contradictory writing, in particular from the viewpoint of emotion and capabilities. We are already familiar with these ideas from the last chapter: for Nussbaum there is no flourishing without activity, and there is no activity without a certain amount of vulnerability,[656] because we are social animals, living in worlds without total control. This leads to our emotions, which also leads us to work, play, and live with others.

For the capabilities approach, however, she couples the capabilities' emphasis on individual choice with vulnerability.[657] In other words, while defending the idea that at the individual level people should decide for themselves what they wish to be and to do, she

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[654] *Ibid.*, p. 150

[655] She argues for this in contrast to contract doctrines, which do not seem to be able to accommodate disabled persons' needs for more resources, because of concerns over social productivity and/or the costs that may pertain to these persons in particular. See: *Frontiers of justice: disability, nationality, species membership,* First Harvard University Press paperback edition. ed., The Tanner lectures on human values. The Belknap Press of Harvard University Press, Cambridge, Massachusetts London, England. p. 135

[656] Goldstein, P., 2011. *Vulnérabilité et autonomie dans la pensée de Martha C. Nussbaum*, 1. éd. Philosophies. Presses Univ. de France, Paris. p. 20.

[657] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 127.

also recognizes that we need others to develop and put into action our capabilities.[658] The CA can be seen as relational autonomy approach, because it advocates that a person's capabilities are significantly shaped by their social circumstances and relationships, not only by individual actions, desires, or resources.[659] We have already seen just how important others are for the PWE's flourishing, or on the contrary how damaging they can be on the person's ability to live well with their disease.

The capabilities approach is therefore remarkable for its focus on promoting individual capability of choice coupled with recognition of individual vulnerability. It supports individual agency, all the while recognizing our fundamental need of others to achieve our ends. If in Nussbaum's approach, we will not advocate for autonomy to the same degree as many bioethics definitions,[660] Nussbaum's innovation is to emphasize our inherent and fundamental vulnerability, even while retaining our right to choose our own lives.

Nussbaum's perspective remains pertinent for our subject. Vulnerability helps us move beyond personal responsibilities put either on the patient or the doctor, and instead helps us think of social responsibility as a plural concept, involving both institutions and a diversity of individuals. It also allows a more nuanced and realistic view of individual choice as linked to the support of others. In addition, by focusing on vulnerability, we can see that by advocating for the right to individual choice, we are not advocating that patients act against their best interests, such as being supported to choose healthcare plans based upon unrealistic expectations. Thus when we combine the idea of relational autonomy with Nussbaum's ideas on vulnerability, it helps us emphasize the importance of affiliation to help persons make realistic life and treatment choices.

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[658] She says that we are looking for "a social good" which shares complex needs with others at many levels and that we flourish only with the help of others. Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. The Belknap Press of Harvard University Press, Cambridge, Massachusetts London, England. p. 158.

[659] Entwistle, V.A., Watt, I.S., 2013. *Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centered Care*. The American Journal of Bioethics 13, p. 33.

[660] See Chapter 1 for discussion of these definitions.

3.3.3. Nussbaum's Threshold of Central Capabilities

Altogether the capabilities approach represents a significant challenge to governmental institutions to better the life of all of its citizens, as defined by people's capabilities *to be* and *to do*. Nussbaum's particular call to arms is for governments to create the conditions for citizens to live a flourishing life, capable of dignity, to a threshold level.[661] She says that as her aim is to, *"provide the grounding for constitutional law and public policy in a nation aspiring to social justice…*(therefore*) selection is of the upmost importance."*[662] Nussbaum proposes a threshold as the minimum for a life of dignity[663] in the form of a list of ten central capabilities that we should promote in our societies. The list is both thick[664] and thin[665] given its substantial content but also flexible enough to allow each country or institution to develop the list according to their own needs.

Nussbaum is the most criticized for the universal proposal of her capability list. According to Deneulin, Nussbaum's first versions of the approach[666] were perfectionist[667] because certain capabilities were promoted even when people do not necessarily desire these capabilities outright.[668] This was justified by Nussbaum because structures of inequality and discrimination might distort what people choose and/or value (what she calls *adapted preferences*). In these early versions of her approach, she sought to enforce capabilities as moral obligations for governments and citizens.[669] Under the influence of her readings of Rawls' political liberalism, she came to defend the idea that human goods were plural and distinct. In the newer versions of her approach, capabilities are now to be promoted not because they represent some distinct and comprehensive notion of the good,

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[661] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. P. 33

[662] *Ibid.*, p. 29

[663] For Nussbaum, beneath the threshold, we cannot consider that a person is able to live in a "truly human way." Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 74.

[664] Nussbaum's list is thick by drawing on Aristotelian conceptions of the good across all areas of human life. It is notably in contrast to Rawls who does not seek to endorse a conception of the good. For more discussion, see: Alexander, J.M., 2016. *Capabilities and social justice: the political philosophy of Amartya Sen and Martha Nussbaum.* Routledge, London. p. 66 and footnote 12.

[665] Nussbaum thinks the list is also a thin moral conception in that it could be harmonized with different moral, religious, and philosophical doctrines. This is her main argument for definition of a list.

[666] The capability approach within the context of an Aristotelian Social Democracy as proposed by her first articles on the subject was later modified with the input of Rawls' contributions on political liberalism.

[667] By this we are referring to the moral theory which regards certain activities as good, independent of any subjectivity. See: Deneulin, S., 2002. *Perfectionism, Paternalism and Liberalism in Sen and Nussbaum's Capability Approach.* Review of Political Economy 14, p. 498.

[668] *Ibid.*, p. 502.

[669] *Ibid.*, p. 506.

but because they are the means in which each individual person could choose and pursue their conception of the good.[670] Thus the goal of public policy is to reach a consensus among different persons. In her modified approach, the capabilities became not *obligations*, but *rights* that could be the basis of constitutional law. By securing these rights, citizens in turn could be free to use these rights as they wished.[671] However, even with this modification, which gives greater space for historical and cultural differences in persons' conceptions of the good, her list continues to be seen as perfectionist. Chavel for instance argues that that the capabilities approach in this reformulation is still a type of perfectionism in the political-liberal sense, by which she means that it is respectful of individual liberties, all the while not sacrificing the ideal of the good life.[672]

Because of this, Nussbaum's list also continues to be criticized as paternalistic. While her modifications to her approach show sensitivity to diverse cultures and traditions, she cannot fully escape this critique. Nussbaum has responded by stressing the flexible use of her list. She says, "*in framing any normative comparison, we need to attend carefully to respect for choice and make sure that we protect the spaces within which people express themselves in accordance with their choices.*"[673] The aim of her list is to provide guidance; she then gives a task to each government and individual citizens and groups to appropriate them in the context of their countries/cultures.[674] We should therefore see her list as a guide, not as the only answer to public policy. As Goldstein has pointed out,[675] Nussbaum's list is intended to be defined in each concrete context, not only in terms of its *definition* (for instance the modification of a list of central capabilities), but also in its

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[670] *Ibid.*, p. 506

[671] Framing the capabilities approach in terms of rights vs. obligations remains contentious. As Deneulin argues, *"if the capability approach really wants to provide a normative framework so that policies can be taken that allow each human being to live a dignified human life, it will have to think the capabilities not as philosophical basis for constitutional guarantees, but as philosophical basis of obligations that all humans have towards one another through the mediation of institutions."* For more discussion on this problem, see: Ibid., p. 518.

[672] Chavel, S., 2010. *Perfectionnisme et capabilités*, in: *La Voix et La Vertu: Variétés Du Perfectionnisme Moral, Ethique et Philosophie Morale*. Presses universitaires de France, Paris. p. 201.

[673] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 107

[674] Nussbaum's guarantees for this are : 1) *multiple realizability* in that each of the capabilities may be realized in different ways, in accordance with differing traditions ; 2) the capabilities approach promotes capabilities, not functioning; 3) the content of the list gives prominence to power of choice and political and civil liberties; 4) it seeks an overlapping consensus through political liberalism; and 5) the approach is intended to offer the philosophical grounding for constitutional principles, but does not impose the implementation of such principles. See: Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 105.

[675] Goldstein, P., 2011. *Vulnérabilité et autonomie dans la pensée de Martha C. Nussbaum*, 1. éd. ed, Philosophies. Presses Univ. de France, Paris. p. 105.

application in concrete contexts and cultures. Nussbaum's particular priority was to use her list as the basis of constitutional law. Seeing capability failures and entrenched adapted preferences in many places in the world, she sought to define a list that would reverse these discriminations and provide the means to promote equality for all citizens (even if this involves to a certain extent "paternalistically" defining that citizens should have access to health and education). If we take into consideration Nussbaum's goal in introduction of her capabilities list, we can understand that modifications of her list may be necessary depending on the individual project and its relevance to the subject at hand.

In the scope of our project, we were aware of and inspired by the capabilities approach at the start of our project. We saw Nussbaum's capabilities list as "vague enough" but also "substantial enough" to work within the context of our project. However, we did not accept the capabilities list right away. In the first place, as the capabilities list is a broad basis for the formulation of constitutional law, analyzing all of the capabilities on her list was too wide for our (smaller) project of patient empowerment. In the second place, as we sought to develop our subject with patients directly, we first and foremost sought to define our subject with our patients. It was up to them to define what capabilities (or whatever else) was important to them. Although we had the capabilities list in mind, we did not for instance ask patients to pick which of the capabilities on Nussbaum's list was relevant to them. Instead we returned to them in our analysis because developing these capabilities was an important theme for patients. In our approach, we have therefore used several capabilities on her list as an epistemic tool to help us unravel patient empowerment from the patient's perspective.[676] Given the "thin" focus of her list, we believe our method remains in keeping with the spirit of this list.

Nussbaum's central capabilities list encompasses ten capabilities. We will list them here in their entirety and then elaborate which of these capabilities were used as epistemic tools to help move toward a patient-developed definition. Her capabilities list encompasses the following capabilities:

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[676] Other leading capability theorists such as Robeyns, while rejecting Nussbaum's capabilities list, have conducted similar exercises as Nussbaum to establish a capabilities list relevant to their particular project. What is remarkable about this type of lists is not only the similar methods involved in the formulation of these capabilities, but also how many of the final capabilities identified resemble Nussbaum's list. This does not mean that we should accept Nussbaum's list without "further ado"; however, if we decide not to initially start from Nussbaum's list, it might be valuable to analyse as a final step Nussbaum's list to spot convergences and disagreements. For her approach to defining capabilities, see: Robeyns, I., 2003. *Sen's Capability Approach and Gender Inequality: Selecting Relevant Capabilities.* Feminist Economics 9, 61–92.

1. *Life. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.*

2. *Bodily Health. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.*

3. *Bodily Integrity. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.*

4. *Senses, Imagination, and Thought. Being able to use the senses, to imagine, think, and reason—and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.*

5. *Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)*

6. *Practical Reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. [This entails protection for the liberty of conscience and religious observance.]*

7. *Affiliation.*
    1. *Being able to live with and toward others, to recognize and show concern for other humans, to engage in various forms of social interaction; to be able to imagine the situation of another. [Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.]*

    2. *Having the social basis of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species.*

8. *Other Species. Being able to live with concern for and in relation to animals, plants, and the world of nature.*

9. *Play. Being able to laugh, to play, to enjoy recreational activities.*

10. *Control over One's Environment.*
    1. *Political. Being able to participate effectively in political choices that govern*

one's life; having the right of political participation, protection of free speech and association.

2. *Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.*[677]

3.3.4. Selected Capabilities

We will now elaborate which capabilities of this list will be used for our project. In the first case, we can say that Nussbaum's capability of bodily health specifically attracted our attention due to the specific topic of our research subject. The possibility to incorporate the patient's view of their own health seemed a first step to understand what result patients were looking for in their healthcare. Thus we have ourselves chosen this capability as one to be explored through our patient's input. However, the other two capabilities to be explored in this Chapter – practical reason and affiliation – are at once highlighted by Nussbaum herself as the overarching architectonic capabilities of her list, as well as being those capabilities that the patients (and healthcare providers) themselves highlighted as important in the interviews we had with them.

Finally, while we will not explore emotions as a specific capability in this chapter, we will frame our results from Chapter 2 within the overall capabilities approach now that it has been introduced. Although we have already investigated how emotions affect patients in their overall lives, in this section we will clarify emotions within the capabilities approach, allowing us to fully understand our research results from Chapter 2.

Bodily Health*: being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.*

The first capability to be explored seeks to secure some basic needs (such as adequate nourishment) along with some basic rights (such as reproductive health) in order to

[677] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. P. 33-34.

guarantee what Nussbaum calls the capability of bodily health. It is closely intertwined with the first capability (life) in that the person should be able to live to the end of life and not die prematurely, as well as capability three (bodily integrity). If we take these three capabilities into consideration, it would appear that health for Nussbaum is defined by a minimal level of "basic human needs" such as being able to live life to a normal length, being able to be adequately nourished, and having shelter; and guarantees of some "basic rights", such as the right to control what may happen to the body (such as through reproductive choices).

Her concern in proposing this capability, from what we can understand from her overall project, is to ensure that all persons have these capabilities met, without which they could not live a life with dignity. Nussbaum calls it *tragic* when one capability on her list is sacrificed for another as all are needed for a life of dignity; in turn, the lack of these capabilities can have a corrosive effect on others.[678] For instance, without adequate shelter or nourishment, it is difficult to imagine how a person can engage in meaningful work (Capability 10) or not to have their lives blighted by fear or anxiety (Capability 5). Introducing health into her capabilities approach is therefore a clear engagement for governments to assure a threshold level of all of these basic entitlements for its citizens.

However, in the wording of this capability, it remains unclear what Nussbaum means by "being able to have good health." She does make a distinction between having good physical (bodily) health and emotional health, given her separation into two capabilities.[679] Thus we may be able to understand that she conceives of bodily health as having an adequate level of nutrition and essential medical care, rather than focusing on the biopsychosocial aspects of health, although we could argue that they turn up specifically in Capability 5. In a footnote in her 2008 book on *Women and Development*, Nussbaum adds confusion by linking this capability to the World Health's Organization (WHO)'s definition, which states that health is, "*state of complete, physical, mental and social well-being, and not merely the absence of disease or infirmity*.[680] She goes on to say that the definition, "*fits well with the intuitive idea of truly human functioning which guides*

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[678] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi., p. 44.

[679] The wording of Capability 5 suggests that here she is referring to emotional health (through emotional development), in particular because she signals in this capability, "not having one's emotional development blighted by fear and anxiety."

[680] This definition of "reproductive health" was defined by the 1994 International Conference on Population and Development. In it, they propose health as a "*state of complete, physical, mental and social well-being, and not merely the absence of disease or infirmity. Ibid*., p. 78.

this list." [681] With this footnote, she has fully muddied her conceptualization of bodily health.

The potential of viewing health as a capability is more robust than in conceptions of health as either an absence of disease or total well-being.[682] It allows us to understand health as the opportunities that persons have in their environments, rather than trying to seek an ideal state of absence of disease or complete physical, mental, and social well-being. We will therefore need to clarify this capability for our project before moving forward. Here we will call on the assistance of Nordenfelt's idea of *vital goals.*[683]

The two approaches are remarkably similar.[684] Nordenfelt's action-theoretical approach to health is interested in what specific actions may lead to a minimal state of happiness. The approach is also concerned with identifying a minimum or a threshold of happiness.[685] An important parallel with the capabilities approach is its focus on the *environment*: the fact that our actions depend on the world outside of ourselves, on our abilities to do something in a given time and place depending on the circumstances. While the capabilities approach might call this "combined capabilities," Nordenfelt calls this an action-chain[686] or an accomplishment of an action requiring opportunities.[687] Both theories however are concerned with flourishing and the important role of opportunities in one's environment.

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[681] *Ibid*., p. 78

[682] Venkatapuram, S., 2007. *Health and justice: The capability to be healthy*. p. 120.

[683] Nordenfelt, L., 1995. *On the nature of health: an action-theoretic approach*, 2., rev. and enl. ed. ed, Philosophy and medicine. Kluwer, Dordrecht.

[684] According to Venkatapuram, Nordenfelt is aware of the capabilities approach and has discussed the similarities and differences of his approach with Amartya Sen. According to a private communication with the researcher, he said that he believes the capabilities theory a more systemic approach to well-being than his concern with vital goals. Venkatapuram, S., 2013. *Health, Vital Goals, and Central Human Capabilities*. Bioethics 27, p. 276.

[685] We object to Nordenfelt's choice of translating *eudaimonia* (flourishing) into the modern idea of happiness. This focus on subjective happiness remains the most comprising – and vague - part of his theory and the one for which he has been most criticized. He partly mitigates this criticism by characterizing "minimal happiness" in a temporality and as multidimensional, which is to say he does not believe that "happiness" means those actions which produce happiness in the short term. He also says that happiness can vary in intensity and frequency, richness, and duration. Thus he is concerned with how to achieve minimal happiness in a sustainable way, which is better characterized, in our view, as "flourishing." Furthermore, he specifies basic *vital goals* as those which are 1) absolutely necessary for happiness and 2) the state of affairs which has proved to add considerably to the patient's happiness in a great many cases. For Nordenfelt, this "state of affairs" is likely to be basic goods but also economic and social security. Because of these factors, and because we are focused on long-term ideas of well-being, for our purposes, we prefer to see Nordenfelt's theory in terms of "flourishing" rather than "happiness" given its emphasis on long-term temporality. See: Nordenfelt, L., 1995. *On the nature of health: an action-theoretic approach, 2., rev. and enl. Ed., Philosophy and medicine.* Kluwer, Dordrecht. p. 82-86.

[686] *Ibid.*, p. 40

[687] *Ibid.*, p. 41

Nordenfelt defines health as, *"a person's ability to realize his minimal happiness."*[688] According to Nordenfelt, *"A is healthy if, and only if, A is able, given standard circumstances in his environment, to fulfill those goals which are necessary and jointly sufficient for his minimal happiness."*[689] By reflecting on what actions a healthy person should be able to realize in a given environment, Nordenfelt takes into account the structural conditions necessary to achieve those goals (the combined capabilities), but also gives considerable flexibility both in what those goals might be (like Nussbaum's emphasis on plural values).

Furthermore, when Nordenfelt talks about "goals necessary and sufficient," like Nussbaum, he is not talking about just any goals, but rather those goals that a healthy person must be able to achieve to realize their happiness. He calls these necessary and sufficient goals, *vital goals*. For Nordenfelt, the vital goals of man are those, *"whose fulfillment is necessary and jointly sufficient for a minimal degree of welfare, i.e. happiness. To be healthy then, is to have the ability to fulfill those goals which are necessary and jointly sufficient for a minimal degree of happiness."*[690]

Venkatapurum has made a pertinent proposal combining aspects of the capabilities and action-theoretical approaches. He proposes that health is, "*a core set of capabilities, representing a minimal conception of human well-being."*[691] His combined approach helps us see Nussbaum's capability as part of a *set of capabilities* to flourish. We should therefore not take Nussbaum's capability of bodily health alone, but combine it with the other nine capabilities. We will see how this idea of a *set of capabilities* corresponds to our patients' perspectives.

Nordenfelt also adds another nuance with his idea of adaptability. He says that, *"adaptability is also a matter of realism: to what extent the subject is prepared to change his ambitions, to reformulate them in light of a new environment. If the subject is adaptable in this sense, some lack of psychophysical strength can be compensated for and the equilibrium between ability and vital goals remain."*[692] Nordenfelt's idea of

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[688] *Ibid*. p. xv
[689] *Ibid.*, p. 79
[690] *Ibid.*, p. 78
[691] For Venkatapurum, health policy under this definition will include more than (just) healthcare, as it will deal with the wider conception of well-being as advocated for in the CA. We take a similar viewpoint through the patient life empowerment approach. Venkatapuram, S., 2013. *Health, Vital Goals, and Central Human Capabilities.* Bioethics 27, p. 276-278.
[692] Nordenfelt, L., 1995. *On the nature of health: an action-theoretic approach*, 2., rev. and enl. ed., Philosophy and medicine. Kluwer, Dordrecht. p. 99.

adaptability helps us to understand that being healthy can also consist in a capability to adapt to new circumstances. We will analyze this idea in our discussion, as it is an important finding reflected from our field research from both patients' and the healthcare providers' perspective.

Emotions: *being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development).*

Martha Nussbaum's capability of emotion has been nurtured by her theory of emotions. We note her specific choice of the word "emotion" over other concepts, such as feeling or passion, to refer to her cognitive-evaluative view that sees emotions as having objects, and that these objects show something of importance to the person concerned (being able to love and grieve others, to have justified anger toward others). Here we see the important aspects of vulnerability present in her Neo-Stoic theory of emotions. Following Winnicott and others, Nussbaum's theory of emotions claims that we need a *facilitating environment* in order to develop healthy relationships to others in our adult lives. This facilitating environment helps us overcome our fear and anxiety and develop into capable adults. The emphasis of Nussbaum's approach is focused on stimulating these basic capabilities in these early development stages, in order to help infants toward a capability to love and care for others through various forms of human association throughout their lives.

In the previous chapter, we have already seen an example of this capability, although we have instead witnessed its failure. We have shown how overprotection by family members has blighted the emotional development of their family members. However, we have also seen that fear and anxiety is not just a question of emotional development in infant development stages, but also remains a fundamental blocking factor in society when the patient is an adult and supposedly the emotional development stage is over. For our project, we will therefore introduce a minor modification to Nussbaum's capability of emotion.

As we have maintained, we may assume that Nussbaum's focus in the wording of this capability is to enable persons to acquire a capability set (with the most important part of the work taking place during child development stages). In Nussbaum's approach, most

resources will go toward this aim. However, given her parallel emphasis on the lifelong pursuit of flourishing as well as on combined capabilities, she also takes a long-term view. For our subject, through the emotion of fear, we have shown that supporting this capability is a matter of the whole life (in work, leisure, and in relationships), and not just a matter of developing it in childhood.

In what temporality a capability level must be achieved and/or maintained remains an unresolved issue in the capability approach.[693] For our purposes, if we can understand that our patients live in a world in which their *capability to flourish* remains blighted by fear due to their diseases, then we have to take the stand that this capability must be developed (internal capabilities) but also maintained (combined capabilities) throughout the lifespan. Given our brain's capacities for ongoing learning throughout our lifetimes — as we have seen with learned helplessness in the case of fear — we argue that the word *development* used in Nussbaum's capability is not fully inclusive. While many resources in the capabilities approach may go towards achieving these capabilities during infancy, they will also need to be nurtured throughout the lifetime of the individual. Thus for our project, we will understand the capability of emotions as *emotional development (not blighted by fear and anxiety) throughout the human life span.*

Our project *with* emotions has now been incorporated into Nussbaum's capabilities list. Through the capabilities approach, we can also now more fully understand the impact of emotions like fear and disgust on the person's capability set. Emotions like fear can turn into capability failures, impeding the person's abilities to live well with their disease and their relationships to others. With the capabilities approach, we can understand that emotions may also have a *cascade effect*, influencing or impeding other capabilities on Nussbaum's list, such as affiliation, practical reason, or even bodily health. When looked at in the overall framework of the capabilities list, we can now see that emotions are part of a *capability set* that can help ensure opportunities for individuals.

[693] In other words, where is the threshold of support in capabilities, is it adulthood or at some other moment in the life span, or indeed does it continue throughout one's lifetime? This is one of Arneson's main critiques of the capabilities approach, in particular Nussbaum's idea of a threshold. See: Arneson, A. *"Distributive Justice and Basic Capability Equality"* in Kaufman, A. (Ed.), 2006. *Capabilities equality: basic issues and problems, Routledge innovations in political theory*. Routledge, New York ; London. p. 24.

***Practical Reason**: being able to form a conception of the good and to engage in critical reflection about the planning of one's life. [This entails protection for the liberty of conscience and religious observance.]*

Nussbaum's capability of practical reason is what distinguishes a life lived with dignity, a life that is "truly human." Our capability to search for, and pursue, our version of the good is central to the capabilities approach. Our capability for practical reason helps us to scrutinize our values and our judgements about which activities are important to us. It gives us the possibility to plan our lives, as well as to decide which activities should be prioritized among others.[694] Nussbaum's capability of practical reason ties us to a certain kind of life, a life in which the individual's *eudaimonia* is sought, instead of a life of forced labor or one (only) concerned with bodily pleasure. According to Nussbaum, and following Aristotle,

> *"Since no life will count as a good life for a human being unless it is first of all a life for a human being, and since a life for a human being must be a life organized, in some fashion, by practical reason, in which all functionings are informed and infused by reason's organizing activity, then eudaimonia must be sought within the group of such lives, not in a life totally given over to bodily pleasure without reason, not in the sleeper's life of non-guided digestive functioning, not in the slave's life of coerced and routinized labor."*[695]

As Nussbaum favors freedom to choose and order capabilities, we can understand here that policy will be one in which an individual's choices are respected. However that does not mean that it is up to the government to prioritize any kind of life. In seeking to promote the capability of practical reason, she is seeking a life of activity, a life of flourishing, for the individual person. A *capability set* will be needed to enable persons to be able to exercise choices, and sometimes functionings will need to be imposed to enable their development (such as having a minimum of education and healthcare). The capability of practical reason is both nurtured by and nurtures the other capabilities on Nussbaum's list. Nussbaum calls this capability *architectural*, for its role in organizing and being present in the others.[696]

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[694] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 39.
[695] Nussbaum, M.C., 1987. *Nature, Function, and Capabilities: Aristotle on Political Distribution*. Wider Working Papers. World Institute for Development Economics Research of the United Nations University. p. 47-48.
[696] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 39.

As we will show, practical reason also remains central to our project from the patient's perspective. From our two narratives at the beginning of the chapter, we can already see that Melanie and Christophe are seeking this capability. They talk about how they are being stimulated and encouraged at the healthcare establishment to develop their capacities to find their life paths. They discuss trying out workshops to see what they are capable of doing in their professional lives. At the Teppe, they are engaging in critical reflection of their lives, in a stimulating but difficult search to find their conception of the good in spite of the long-term aspect of their diseases.

Affiliation

1. Being able to live with and toward others, to recognize and show concern for other humans, to engage in various forms of social interaction; to be able to imagine the situation of another. [Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.]

2. Having the social basis of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species.

Affiliation is the other architectural capability which pervades and stimulates the overall capability set. For Nussbaum, affiliation means being respected as a *social being* (familial, friendly, group-based, political, etc.)[697] In this capability, we can see the full potential of reciprocity. It is not only a question of being able to live *with* others, but also *toward* others. Nussbaum sees our ability to show concern, to empathize, as essential capabilities to enable us to live in society, to engage in valuable forms of social relationships both for those receiving assistance (*being cared for*) but also for those giving their assistance (*caring for*). It is not only a question of what others can do for me, but also what I can do for them.

In *Frontiers of Justice*, Nussbaum extends the idea of reciprocity to persons that are traditionally left out of social justice, notably severely disabled persons. She conceives of a wide view of reciprocity, as she believes that helping all persons get to a threshold level of capability helps society as a whole, by giving a more diverse group of people from which

[697] *Ibid*. p. 40.

to interact.[698] In Nussbaum's approach, we will see the full potential for social reciprocity for our patients, for those borderline cases that are traditionally left out of such conceptions. With the capabilities approach, our patients will become fully integrated because of development of their *capability set* not only allows them to receive, but also to give assistance, love, and friendship.

Nussbaum's capability of affiliation makes a clear stand that living with dignity, living *with* and *toward* others, means being respected as an individual whose worth is equal to other persons. The capability of affiliation is therefore focused on both fostering interpersonal relationships, but also gives the task of governments to ensure that persons are treated as equal in law. It is therefore also one in which the government may intervene to ensure that persons are treated equally.

Nussbaum gives the example of employment options: she says that just making employment options available without taking into consideration workplace relationships will be an inadequate means of addressing discrimination. As we saw from our patient's capability failures in the workplace, it was not enough to create special provisions in the law for persons with epilepsy; even if they were able to integrate workplaces, their capability to work *with* and *toward* others in these workplaces was still absent, as they were not treated as dignified beings in these spaces (as Mei Ling showed us). This capability thus helps us see why government programs for such situations are necessary but not sufficient, as they do not take into account the other kinds of relationships in the workplace (such as the interpersonal relationships between colleagues). For Nussbaum, *"relationships of many kinds (familial, friendly, group-based, political) all play a structuring role."*[699]

In light of this capability, we can now more fully understand our fieldwork from Chapter 2. We can now see that due to fear in its many forms, our patients have missed out on this capability of affiliation, thereby affecting their overall capability set. As we saw with fear, this in turn had a corrosive effect on their other capabilities, including their capability to be in good health. Affiliation will continue to play an architectonic role in the development of our approach in order to understand how patients can live well as social

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[698] Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. The Belknap Press of Harvard University Press, Cambridge, Massachusetts London, England. p. 129.

[699] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 41.

beings. In this chapter, we will focus in particular on the doctor-patient relationship and patient-to-patient relationships. This discussion will help us unravel the patient's understanding of these relationships and what they want and need from them.

These are the capabilities we will explore to develop our patient developed approach. Before continuing with our research results, however, let us first highlight the strengths of the capabilities approach over the current empowerment approaches we have been discussing.

3.3.5. The Capabilities Approach vs. the Empowerment Approach

Now that we have detailed Nussbaum's contribution to the CA, let us now see how the approach might be different or complementary to current empowerment approaches. At the time of writing, we were not aware of specific proposal conceptualising patient empowerment from the patient's perspective using the capabilities approach.[700] Articles related to patient empowerment and the capabilities include evaluations measuring women's empowerment in terms of decision-making related to their health and a proposal for a health functioning model. [701] [702] Most of these interventions seek to use existing ideas of empowerment to create new models or evaluations through the capabilities approach; they do not however seek to reformulate the empowerment approach with the capabilities approach and/or patient's contributions, which is the innovation of this research project. Given these limitations, in this section we will largely rely on our own reflections of what the CA might bring to our subject.

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[700] There is however a proposal of how the capabilities approach can be implemented into patient-centered programming. See: Entwistle *et al*. See: Entwistle, V.A., Watt, I.S., 2013. *Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centered Care*. The American Journal of Bioethics 13, 29–39.

[701] Another example of a related empirical study was by Grewal et al., which used in depth interviews to determine the aspects important for the quality of life of older people, and suggested that capabilities might be the relevant analysis to understand quality of life for this group of people. They argue that it is not *poor health* per say which is a problem, but the *capability* to do things because of poor health which influenced the person's quality of life. See: Grewal, I., Lewis, J., Flynn, T., Brown, J., Bond, J., Coast, J., 2006. *Developing attributes for a generic quality of life measure for older people: Preferences or capabilities?* Social Science & Medicine 62, 1891–1901.

[702] For an overview of the applications of the CA to healthcare, see: Mitchell, P.M., Roberts, T.E., Barton, P.M., Coast, J., 2017. *Applications of the Capability Approach in the Health Field: A Literature Review*. Soc Indic Res 133, 345–371.

Patients as Agents

In the first place, in the CA, the subject of justice is the individual, who has the right to choose and act on their conception of the good. The priority is to develop and support the individual's freedom of choice. Understanding healthcare using a capabilities perspective is demanding as it asks both to help the patient cultivate their capabilities and to respect individual patient's choices. With the CA, the task of the healthcare institution and healthcare providers will be, to the extent possible, to help patients toward capabilities which they could not develop on their own (such as helping them understand their disease and their treatment), but then to engage in respectful action. It means helping patients toward a threshold level of capability, but afterwards leaving them free to use these capabilities as they wish. The capability approach's focus on the centrality of individual choice remains an important one. While such an emphasis on individual choices may be an ideal in some situations, it at least reminds us (as healthcare providers, as patients) that the choice which is to be advocated and defended is the patient's.

Formulating the capabilities approach for healthcare means recognition that it is for patients to decide and act upon their ideas of the good, notably because we are seeing and recognizing persons as agents. Nussbaum follows Aristotle's emphasis on becoming empowered (developing capabilities) vs. functioning, by saying, *"Aristotle is very careful, here again, to stipulate that it is exousia, authorization or being-empowered, that we are after here, and not actual functioning."*[703] This focus on capabilities vs. functionings provides a counter to existing patient empowerment approaches, which seeks to impose certain functionings on the patient, to behave in a certain way in order to favor adherence and thus reduce healthcare expenditures.

Current empowerment approaches also focus on the collective good vs. individual good in the form of reduced healthcare costs for society. With the capabilities approach, we put the focus clearly on the individual and what result they are seeking, as well as the support they might need in their social environments to acquire and use these resources.

Patients as Social Beings

The capabilities approach also conceives of the person as a social being in a different way than in some existing empowerment approaches. These approaches see (or

[703] Nussbaum, M.C., 1987. *Nature, Function, and Capabilities: Aristotle on Political Distribution*. Wider Working Papers. World Institute for Development Economics Research of the United Nations University. p. 24.

rather try to favor) the patient as mostly an autonomous being, capable of becoming empowered and afterward needing fewer resources from healthcare institutions. By recognizing rights to autonomy, these approaches concurrently seek to make the patient responsible for their healthcare behaviors. In the capabilities approach, on the other hand, we can embrace the full recognition of our neediness as social beings, both within and outside of the consultation. The CA also allows us to understand that patients are vulnerable; that they need the help and support of others to elaborate and act on individual choices (and that this is not necessarily a bad thing!). What this might imply is that we will need to give a new task to healthcare providers: helping patients toward elaboration of their capabilities.

New Temporalities

In the capabilities approach, we are also displacing the temporality of when empowerment may be achieved. Elaborating capabilities takes time. It will be unsuccessful unless it follows the rhythm of the individual patient. As we saw in Chapter 1, while some patients may be empowered from the very first consultation, many others will develop their capabilities in a gradual process that includes accepting and appropriating their disease and treatment. Patients will need assistance to build upon capabilities that are already present or will need to be developed from scratch. For this to happen realistically, we will need to *heal our institutions* to enable doctors to be able to provide this support to their patients. If this is not possible given the realities of healthcare today, then we need to conceive of alternative ways to support patients beyond the consultation in elaboration of their capabilities.

Working with Borderline Cases

Nussbaum's capabilities approach takes a firm stand on working with borderline or difficult cases which might be forgotten in current empowerment discourses, which seek to work with "already capable" patients, such as patients who afterward could be considered as "experts." Some patients with severe diseases like epilepsy – which can implicate significant cognitive difficulties - can never realistically be expected to become patient experts, or even to be able to make their own decisions without considerable assistance. The CA reminds us that these cases are not to be forgotten, and that these capabilities can be nurtured to help *all* patients toward their own choices. The threshold of capability may not be the same as other patients, and some may never be able to break free from a

surrogate. However even those with significant cognitive difficulties can be nurtured toward their *capability set*. As the capabilities approach recognizes these persons as agents, it also means they deserve our full attention.

Integration of the Environment

Another strength of the CA is that takes into focus the importance of the environment — and others in their environment — on the ability for patients to live well with their diseases. Intuitively, the CA aligns with patient empowerment's focus on development of one's capabilities in order to be empowered to act. However, existing empowerment approaches assume to a certain extent that the once empowered, persons will simply be able to translate these capabilities into functioning. Here is the advantage of the capabilities approach over the current patient empowerment approach: in order to function (or to translate our capabilities into functioning), the right social, political, and economic conditions will need to be met. The capabilities approach helps us to see that we need both the right environment in which to act on our capabilities, but also considerable assistance to be able to overcome the historical, social, and familial sequelae of discrimination that have resulted in distorted visions of capabilities.

With and Beyond Legislation

We have seen a clear example of a capability failure in Chapter 2: fear and the resulting overprotection by family members result in patient dependence on family members or healthcare providers to make decisions for them. Because of disabling factors such as these in their social environments, many patients currently have a low capability to make their own life choices. In the capabilities approach, we can see that providing the legislation or developing programs for patient empowerment is not enough. If all patients technically have the right to decide their healthcare plan, in practice only a certain percentage of the patient population can use it due to these failures. By using the capabilities approach, we will incorporate, but also move beyond legislation and involve institutions, families, and individuals to help reduce or eliminate these failures and to give back agency to the patient.

A Clarification of Responsibilities

To terminate this discussion, let us highlight one further point. In patient empowerment discussions, individual responsibilities of the patient to work toward healthcare outcomes are prioritized. Most programming has been developed with this aim in mind. However, what the CA brings to the discussion is that we cannot punish or expect patients to take full responsibility for actions for which they are (actually) unable to implement in practice. We can only expect patients to take this responsibility once they have reached a certain threshold of empowerment (a *capability set*), allowing them to be capable of acting in their environments. We have investigated the detrimental aspect of fear in inhibiting patients from exercising choice. Until we deal with society's fear, we cannot expect those patients (or at least those with socially stigmatized disease like epilepsy) to be empowered. With the capabilities approach, we can therefore engage a larger social responsibility for many actors in helping the patient live well.

3.3.6. The Capabilities Approach for Public Policy

Having outlined the main advantages of the capabilities approach for our topic, we will now detail three main unresolved issues in the capabilities approach. There are many criticisms and reformulations of the capabilities approach in existing literature; we will not repeat these here. What interests us is Nussbaum's central capabilities list and the possibility to translate some formulation of it into public policy without distortion or tragic choice, notably by her list forming the basis of state level laws and institutions. In other words, we are mainly interested in the difficulties of translating the capabilities approach's political ideal into a political reality.

Although there have been policy proposals stemming out of the capabilities approach for use in public policy, including evaluations or propositions for healthcare, the capabilities approach as a wider political project largely remains unfulfilled. If we adhere to Nussbaum's approach, we will need to pay attention to systemic political change, as she says that her aim is, *"to move beyond the merely comparative use of capabilities to the construction of a normative political proposal that is a partial theory of justice."*[704] Given that Nussbaum's capabilities approach is aimed at this ambitious political goal, it will need

[704] Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 6.

to go under a litmus test of feasibility to understand whether or not we can realistically imagine its formulation (and at what level). To unravel this discussion, we will discuss several of Nussbaum's ideas. The first is Nussbaum's partial theory of justice, which seeks to make the theory a realistic goal to achieve in today's societies. We will then discuss her conceptual leap from individual choices to national level policy. Finally, we will provide the CA's response to Bauman's critiques of individual responsibility in today's light capitalist systems. Through these three criteria, we will be able to understand what a society based on capabilities might look like and what we might need to get there.

A Social Justice Theory for Capitalism?

In order to reformulate political change at a national level, Nussbaum has proposed a partial theory of justice, stopping at a threshold level. Although her partial theory of justice may translate into large-scale interventions to achieve a threshold of central capabilities, the approach does not address inequalities above the threshold.[705] This is her solution to propose the capabilities as a realistic goal for public policy in today's systems, without a full upheaval. Critics of the capabilities approach such as Bagchi say that the capabilities approach has not gone far enough by envisaging a world with capabilities but without radical systemic change. Bagchi notes that as many capability failures result from the capitalist system, capabilities as a political priority will remain unrealistic (or only for a select few) if we maintain our current system.[706]

However, even if the economic order were different, Nussbaum does not recommend a fully egalitarian system. For Nussbaum, active striving is an important quality to maintain, because it is a fundamental part of flourishing, an activity which she believes will be difficult to maintain in an egalitarian system.[707] Her justification to stop at the threshold level of capabilities stems from both the priority to maintain this quality but also her wish for the capabilities to be a realistic political proposal.

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[705] Arneson, A. *"Distributive Justice and Basic Capability Equality."* in Kaufman, A. (Ed.), 2006. *Capabilities equality: basic issues and problems*, Routledge innovations in political theory. Routledge, New York ; London.p. 27.

[706] Baghchi's words are, *"a very large proposition of the contradictions faced by the poor when they are exercising their choice can be attributed to competition and struggle for survival under existing capitalism…it is something that leads to the redefining of national goals, sectoral compositions of gross domestic product, and into the structures of firms, relations with the family and in short, into all human relationships."* Bagchi, A.K., 2000. *Freedom and Development as End of Alienation?* Economic and Political Weekly 35, p. 4418.

[707] Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 69.

The Sufficientarian Critique

The capabilities, and especially Nussbaum's approach, have also been accused of being sufficientarian.[708] Critics such as Arneson notably complain that the capabilities approach overstates the moral importance of sustaining all persons at a sufficiency level.[709] Nussbaum's choice of a threshold notably raises problems such as how to get *all* persons to a threshold level of capabilities: therefore we must ask in what temporality a capability level must be achieved and/or sustained;[710] who is included in the idea of "everyone"[711]; and when we can claim that capabilities have been achieved to a threshold level.[712]

We have already explored Arneson's temporality critique in relation to emotional development and proposed our own answer in the context of this research project, by showing that capabilities should be developed and nurtured throughout a person's lifespan. In answer to the second question, however, we have elaborated that Nussbaum's approach includes those with significant disabilities. Nussbaum says that we need to help each and every person to achieve their greatest threshold of possible capabilities, even if it is not possible to get to a certain threshold level in independence without surrogates; however, even in these borderline cases, developing the individual capacity for choice remains the priority. However, this leads to the third question, namely how much is enough? Arneson has argued for trade-offs[713] in order to maximize efficiency among capabilities in situations of resource scarcity; Nussbaum, however, believes that trade-offs among her central capabilities lead to tragic choice.[714] According to her,

> *"Any situation in which we must push some citizens below the threshold on even one of the capabilities is a tragic situation. We are asking them to forego something on which they have entitlements based on justice. Even if the reason we do this is to get them above the threshold on another capability, what we are doing is morally unacceptable. By seeing the situation in this way, as a tragic clash of right with*

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[708] Arneson, A. *"Distributive Justice and Basic Capability Equality."* In Kaufman, A., 2007. *Capabilities Equality Basic Issues and Problems*. p. 17.
[709] *Ibid*., p. 27.
[710] *Ibid*. p. 24.
[711] Arneson's main problem with this idea is that it could both include everyone, what he calls the "global sufficiency doctrine" or that it could lead to discrimination, such as the idea that "everyone" means a certain ethnicity. *Ibid.*, p. 24.
[712] In other words, "how much is enough?" Here Arneson takes issue with the idea that it will be of primary moral importance to get people to the threshold but afterwards a matter of relative indifference what happens to them above the threshold. He also argues that this will not be efficient, as it will not be possible to get certain people above the threshold and will therefore result in a loss of resources. *Ibid*., p. 26-31.
[713] *Ibid.*, p. 14-15.
[714] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 37.

> *right, we prepare ourselves to design a better future, one in which such tragic clashes will not appear."*[715]

While Nussbaum proposes that tragic choice can lead to creative policy change, by ensuring that such types of tragic choice never happen again, the difficulty of advocating for the capabilities approach without distortion and in light of resource scarcity remains a difficult political task. We will return to this issue at the end of this discussion to see what the CA can offer.

Nussbaum's Conceptual Jump: The Individual to the Nation

For capabilities theorists like Nussbaum, the individual remains the focus of social justice. From the individual level, however, Nussbaum jumps to the state level, saying that her capabilities list can be assured via laws, and even better, in a nation's constitution. Here lies a giant conceptual leap between the individual level of choice and the choice of the nation, which will ensure that those individual capabilities are developed and achieved. Her justification for such a leap lies in ensuring the capabilities' sustainability; however she does not give a satisfactory answer of how to identify these national priorities *with* the individual. In other words, we are again facing the problem of epistemic contribution.

Sen and Nussbaum's answer to defining public policy priorities is public deliberation in democracies, should it be through elections, public debate, or protest. Nussbaum says that, *"nations — reasonably democratic ones, at any rate — are systems of principles and laws that have their ultimate source in the people. They are thus important expressions of people's autonomy, that is, their entitlement to live under laws of their own choosing."*[716] We are concerned that this focus on public deliberation as a means to ensure epistemic contribution is not only unrealistic, but will be compromised in situations of resource scarcity. For instance, such a national focus may lead to "tragic choices" or to choices that will only benefit certain groups, especially those in power or behind the scenes influencing that power. This is a problem of epistemic injustice, in that certain groups will not be involved in public deliberation about the relevant capabilities to which they will be entitled. Nussbaum's conceptual jump therefore seems unjustified unless we can think of a realistic and meaningful way to ensure individual, intermediary and non-governmental

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[715] Nussbaum, M.C., 2000. A*ristotle, Politics, and Human Capabilities: A Response to Antony, Arneson, Charlesworth, and Mulgan*. Ethics 111, p. 127.
[716] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 113.

epistemic contributions to formulations of capabilities policy at a national level. If the capabilities approach is serious about public deliberation, then it needs to find new ways for local and alternative (non-governmental or informal) initiatives to have weight into national-level policy discussions, otherwise the individual point of view will likely be sacrificed to politics or national level priorities.

At the end of this chapter, and in relation to our topic, we will show how important it may be to define such capabilities at a national level to provide guidance for our institutions. While we will not have solved the problem of how to ensure individual epistemic contributions in the formulation of such national-level policies, we can show how formulation of capabilities that took place at the national level (through laws and institutions) did give the means for epistemic contributions of patients at a local and individual level into their care plan by keeping the importance of epistemic contribution in mind in policy development. The input of patients into the design of such national-level policies is still absent; however, Nussbaum's focus on creating the means to ensure such capabilities in a sustainable way at a national level does go part of the way to ensure epistemic contributions, if such laws are formulated to require epistemic contributions in the field. We will show how this was possible with the patient life empowerment approach at one particular institution.

The Capabilities Approach and Individual Responsibility

This leads us to the final concern with the capabilities approach in our current societies, notably the capability's stance on social and individual responsibility. In his book *Liquid Modernity*, Bauman criticizes current ethical and political discourse, which has moved from the framework of a "just society" to that of liberal theories, such as "human rights," where individuals have the right to pick and choose their own models of happiness.[717] Bauman says that we overemphasize the individual capability for choice in such models. According to him, *"the yawning gap between the right of self-assertion and the capacity to control the social settings which render such self-assertion feasible or unrealistic seems to be the main contradiction of fluid modernity — one that, through trial and error, critical reflection and bold experimentation, we would need to learn to tackle collectively."*[718] For Bauman, the concern with giving individuals the right to pick and

[717] Bauman, Z., 2000. *Liquid modernity*. Polity Press ; Blackwell, Cambridge, UK : Malden, MA. p. 29
[718] *Ibid*., p. 38

choose their lives in liberal theories translates into advocacy for individual responsibility, which in turn makes it easy to blame the individual for failures. He also emphasizes how limited choice actually is for most individuals. Thus if we use Bauman to criticize the CA, we can say that although the liberal aspect of the approach may lead to policy priorities that advocate the individual's right to choose, then we also have to deal with who is responsible for supporting these capabilities and who is responsible once these capabilities have been achieved.

The CA, however, does have a valuable response to this dilemma. In the first place, the CA seeks to support individual freedom of choice, by focusing on capabilities rather than functioning. If people are viewed as agents under the capabilities approach, because of their capability of practical reason, the approach does encourage people to take individual responsibility for these choices. However, as the capability approach supports a reciprocal view of responsibility wherein individual responsibility is nurtured through social responsibility, the approach considers the environment in which these capabilities are developed and exercised, rather than seeing the individual as an autonomous decision maker fully responsible for these choices.

With Bauman's analysis, we have seen how society is encouraging a do-it-yourself fear where the responsibility for not getting a job, not integrating into society, and not achieving good health is put onto the shoulders of the individual. In terms of patient empowerment, today we see advocacy for patients to learn about their disease in order to achieve better healthcare outcomes. However, rather than only advocating only for individual responsibility, the CA emphasizes the supporting environment in which those choices are made. In line Aristotle's understanding of individual responsibility, the CA seeks only to require individual responsibility for those acts which are under the control of the agent exercising them.[719] It recognizes that most actions are what Aristotle calls "mixed actions," and that most decision-making is embedded in relationships and in our environments. Because of this, the line between voluntary and involuntary action is not easy to unravel.[720]

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[719] Aristotle's view of responsibility is that individuals are only fully responsible for those actions which are voluntary (i.e. the cause lies in the agent, who knows the circumstances of the actions). See: Alexander, J.M., 2016. *Capabilities and social justice: the political philosophy of Amartya Sen and Martha Nussbaum*. Routledge, London. p. 108.

[720] Aristotle says that the "mixed nature" of human actions means that most are neither completely voluntary nor involuntary. *Ibid.*, p. 110.

This is what leads capabilities theorists to say that people are only responsible for their choices once capabilities have been achieved. While this might seem to imply that individuals achieving a certain threshold of capabilities should then be responsible for these choices (and thus blamed!) the capabilities approach even then argues against such easy demarcation, as most actions, even under optimal circumstances, remain mixed actions. This leads capabilities theorists to refuse to make entitlements conditional on such choices.[721] Instead the focus remains on designing institutions favorable to supporting and developing citizens' capabilities to be agents.

Thus the capabilities approach envisions a broader scope for social responsibility, with a more realistic view of individual choice tied to the person's environment. It represents a serious challenge to the idea of individual responsibility in today's liquid modernity: instead of placing all the blame on the individuals, it instead asks us as a society to support each other to achieve our capabilities[722] and not to blame individuals for capability failures. This more realistic view of individual responsibility remains an attractive feature of the CA, which partly provides an answer to Bauman's dilemma, but it is also one which remains difficult to advocate for in today's societies that validate the individual (and individual responsibility). For such ambitious aims of social cooperation, advocating the capability's idea of individual responsibility will likely require a wider social democratic structure[723] than we have today (and even then, only in a few select countries!).

Efficiency and Efficacy

In light of all of these concerns, even though Nussbaum's vision does not advocate for full system transformation, the CA remains demanding, as getting all persons above a threshold level of capabilities may require extensive economic resources. In order for the capabilities approach to be realistically supported in today's societies, it will likely need to be justified in terms of both *efficiency* and *efficacy*. If justified in terms of *efficiency*, it could be that some persons will be excluded (especially those "worse" off, or needing more assistance); if justified in terms of *efficacy*, then economic savings would likely need to be quantified, which may not be a successful way to promote the CA as it may demand

[721] *Ibid.*, p. 112.
[722] *Ibid.* p. 124.
[723] *Ibid.*, p. 124.

significant resources, especially for those with greater needs to get to the threshold capability set.

Thus we return to the question of when is enough, and who is it enough for? Amartya Sen's response to resource scarcity is to say that we only have to ensure that we do not choose an alternative that is worse than other. This "satisficing" interpretation can lead to policy directions that lead to improved capabilities in certain areas (healthcare for instance), while keeping the status quo in other areas (such as education), as long as it is no worse than available alternatives.[724] This seems to be a realistic way to envisage the CA for public policy, although it will likely remain contentious which policy direction is worse off than others and who gets to decide,[725] potentially leading to epistemic injustices.

Therefore, while the CA invites individuals, collectives, and nations to imagine their social responsibilities toward one another, it does not give us a clear path to get there. Here Nussbaum's focus on inputting capabilities into institutions in durable forms (such as laws) comes to be seen as promising, because instead of advocating for change such as through development of capabilities sensitivity in *individuals*, Nussbaum focuses on state level institutions and their possibility to enter the "hearts and minds" of populations. Once we have developed our patient life empowerment approach, we will look toward national policy that could help make our approach a reality in today's institutions. By institutions, here we mean both the state, as a proposer and regulator of laws, and institutions organized and regulated either fully or partly by the state by these laws, in particular healthcare institutions. However, in our selection, we are not discounting that such actions can very well take place in smaller collectives (such as patient associations) and for individual needs (such as in specialized hospitals).

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[724] *Ibid.*, p.93.

[725] Nussbaum and Sen would suggest this should take place through social deliberation; once again, we hesitate to unconditionally support deliberation as the answer depends on how democratic participation happens on the ground in today's democracies. For a discussion on social deliberation, see: *Ibid.*, p. 115-116.

3.3.7. The Capabilities List as an Epistemic Tool

Now that we have explored the CA and its innovation for our topic (as well as its limitations), let us now detail how we used it as an *epistemic tool* to help us define the patient's conception of empowerment. Because many theorists continue to be stuck on debate on Nussbaum's proposals, notably whether or not there should be central capability list[726] and whether her list is a pertinent ambition for the composition of laws/constitutions, we did not find it fruitful to propose new capabilities to Nussbaum's list. We have instead used several capabilities in Nussbaum's list as an *epistemic tool* to help us in our analysis and conception of the patient empowerment approach.

What we mean by *epistemic tool* is that we will first determine which capabilities on Nussbaum's list were identified by patients as important. We will then seek to analyze patient contributions with the help of Nussbaum's philosophy in order to unravel what these capabilities might mean to the person's flourishing. The final step of our method will be to determine what elements of our discussion are relevant for the patient life empowerment approach. We therefore call our method in this chapter *with* capabilities, as we will use these capabilities to help organize and analyze patient contributions.

Our ambition in this chapter has a practical aim: by starting with the *what* (what matters for the patients), we will ultimately try to conceive of the *how* (the means to get there) from the patient's perspective. The three capabilities identified by myself and patients (health, practical reason, and affiliation) will help conceptualize the patient's perspective of empowerment. In our selection, we are not discounting other capabilities on her list; we take a global view, in line with Nussbaum, that development and maintenance of a capabilities set are needed to enable patients to flourish in their environments.[727] We chose these particular capabilities because patients themselves discussed these capabilities in the interviews. As we are seeking epistemic contributions from patients, it was the research participants themselves that showed to us the pertinence of these capabilities for the approach.

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[726] Nussbaum's list has neither been fully accepted in the capabilities community nor by extension advocated for in a cohesive voice from its community. It is also why additions to the list remain controversial. For an example of a recent proposal for inclusion to Nussbaum's list, see Miranda Fricker's proposal to introduce epistemic injustice to the capabilities list. "Fricker, M. *"Epistemic Contribution as a Central Human Capability."* In Hull, G., 2017. *Equal society - essays on equality in theory and practice*.

[727] For instance, the capability of play could be a relevant capability to take into consideration; however, for the patients interviewed, the possibility to *work* was prioritized (to live *with* and *toward* others in a professional life). Whether play may be relevant to the patient life empowerment definition remains to be explored with other groups of patients.

However, here we can ask the question of, *"then why not just ask patients themselves to define empowerment, would this not be a better epistemic tool than using the capabilities list?"* This was indeed the first step of our approach. However, the problem with this method is that patients had not necessarily heard of the term of patient empowerment (*patient acteur*); while others confused it with the roles *expected* of them as patients. Indeed this was the first surprise of the research process, suggesting that in its current formulation, patient empowerment had little meaning for patients themselves. In addition, it must be taken into consideration whether the research participants' answers showed adapted preferences.[728] Since patients did not necessarily appropriate nor understand the idea, we will need additional tools to help patients toward their definition of patient empowerment, which the CA provides.

In Chapter 2, we have discussed the methodology and fieldwork sites that were used during this research project, although at that time we focused on how we developed the method *with* emotions to identify the salience of the emotion of fear. As we can now understand, our method *with* emotions was the first step in identification of the capabilities relevant for patients in their ideas of patient empowerment. However, with the difference of the method *with* emotion, which used several methodologies (participant observation, interviews, and theater) and several research sites to solicit the epistemic contributions of patients, in order to develop the patient life empowerment approach, we relied principally on the focused ethnography and in depth interviews conducted at the social-medical center of the Teppe. The choice of this site was due to the depth and temporality of this particular site, as well as the possibility to solicit the healthcare provider's perspectives to better understand some responses[729] given by patients.[730] The Teppe was the only site in which we could do this in a satisfactory way as other methodologies (such as the theater) took place in spaces outside of a formal healthcare institution.

In the in depth-interviews, patients were asked directly what they understood as patient empowerment ("What do you understand by patient empowerment?"). This

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[728] For a discussion on the problem of adapted preferences, see: Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 81-84.

[729] Like any institution, the Teppe has vocabulary specific to itself. This vocabulary, which is commonly used by both patients and doctors, is often unfamiliar to the outsider such as myself and needed additional explanation.

[730] However, it is to be noted that our findings do not conflict either with the other French sites or with the Chinese research site. However since the idea of patient empowerment is currently not well-known in Chinese institutions or by patients themselves, it would have been difficult to rely on data gathered from this research site for this part of the research.

question was problematic, because patients did not necessarily understand it. However, it (and the other research question, "Please tell me about your epilepsy?") did give a springboard for discussions on their roles as patients, what result they were looking for in their healthcare, and what was health for them. These questions therefore gave several useful directions for further analysis and development of the patient life empowerment approach.

In the first place, this exploration with patients showed the pertinence of the overall framework of the capabilities approach, because patients in their narratives focused on what they were or were not able to do because of their disease, as well as the opportunities (work or otherwise) available to them in their environments. If some patients were not interested in an empowered relationship with their doctor (and were happy to let their doctor or family decide), all of the patients interviewed were interested in their life opportunities, should it be to engage in work and leisure activities, or to be in various social relationships with others. Therefore having determined that the capabilities framework was pertinent to the patient's perspective, as a second step of the analysis it was necessary to determine if any capabilities in Nussbaum's list were prioritized by patients themselves. During this stage, several of Nussbaum's capabilities were identified with patient contributions, in particular the capabilities of health, practical reason, and affiliation. It was therefore possible to return to the data and contextualize their responses within these particular capabilities. As a third step, conversational analysis of the interviews helped to understand when and in what circumstance patients described their actions/behaviors in either active or passive ways, and what vocabulary they used. These overall findings were contrasted with the healthcare providers' interviews to better understand in what ways patient's descriptions were specifically a reflection of the healthcare service at the Teppe and how these conceptions differed from healthcare providers. We therefore summarize our method *with* capabilities, and *toward* a patient-developed approach of empowerment as the following:

Table 10: Method with Capabilities

-	Asking patients directly what they understand as patient empowerment (*patient acteur*)
-	Thematic analysis to understand what patients defined as important to "live well" with their epilepsy and organization into themes (capabilities)
-	Conversational analysis to note when patients described in active or passive ways their ability to plan their lives, including their healthcare plan, to understand in what ways and where patients seek agency
-	Comparison with healthcare provider interviews/perspectives

From this analysis, the *patient life empowerment* model is proposed. By taking patients as the source of knowledge, by identifying what resources and opportunities they are looking for in order to live well with their disease, we argue that we have moved *toward* a patient-developed definition of patient empowerment. It is for this reason, however, that we qualify our work with a modest contribution "toward" a patient-developed definition. We encourage new formulations and new research in this direction, with new methods, to solicit epistemic contributions from a diverse range of patients. We have gone part of the way toward a patient-developed approach with the epistemic contribution of one particular group of patients through our method *with* capabilities; future research will hopefully solicit other groups of patients to test and further develop the patient life empowerment approach.

3.4. Toward a Patient Developed Approach

We will now move into the main aim of this chapter, which will be to conceptualize the idea of patient empowerment from patient contributions. To structure our discussion, we will return to three key capabilities identified from Nussbaum's list, namely 1) health, 2) practical reason, and 3) affiliation.

3.4.1. Health

As stated in the previous section, we will use Venkatapurum's converged definition of health as "*a core set of capabilities, representing a minimal conception of human well-being.*"[731] Let us start our discussion by first seeing what our patients identify as being healthy. Patients in this research project identified three interlinked ideas of health, including:

1) The disease is not active (there are no seizures)
2) The disease has been stabilized and/or cured
3) The disease does not prevent them from implementing their life projects even if the disease is not completely stabilized (or cured)

In the <u>first</u> definition, patients identify the period when the disease is not active as being healthy. In other words, they identify being in a seizure as "unhealthy" and all other temporalities as healthy. In this respect, they identify with a fairly common (and contested) definition of health as an absence of disease. This is a bit paradoxical, as patients do have a disease; however, for them being healthy is when there are no *symptoms* of the disease (in other words when they are not in seizure). This paradox is due to the specific nature of epilepsy, in which the disease only presents itself in certain temporalities. When patients with epilepsy explain their disease to outsiders, they often use this definition to show that most persons with epilepsy are healthy (like them!), except when the disease occurs. This concept is therefore also used to reduce society's fear of the disease.

However, even if we can understand that some patients identify being healthy as being *without symptoms* of their disease, most patients interviewed at the Teppe said that they were not healthy even in the times *outside* of seizures. This unhealthiness was for

[731] Venkatapuram, S., 2013. *Health, Vital Goals, and Central Human Capabilities.* Bioethics 27, p. 276-278.

diverse reasons. In the first place, the sequelae of seizures cause cognitive difficulties, affecting PWE abilities to be fully active in the immediate temporality after their seizure. Secondly, many patients said it was not the *symptoms* of the disease, but the *side effects* of medication that made them unhealthy. A third element is the fear of seizures. Therefore while some patients saw themselves as healthy in all temporalities in which the seizure was not present, they also highlighted difficulties to be healthy even when these seizures were not occurring. However, what we can retain from this first idea is the possibility to "be oneself" taking place in a temporality *between* seizures. As Nussbaum would say, Christophe was not capable of *striving* toward his good when he was in a seizure. Thus being healthy for Christophe is connected the idea of being active, of pursuing his life projects.

Let us now proceed with the second definition patients have identified as being healthy. Here patients signaled the importance of stabilizing (or reducing) seizures in order to be healthy. Given that being in a seizure was seen by patients as unhealthy, they saw having less seizures as being healthy. This view also harmonizes with the biomedical perspective of epilepsy patient care, as there are at least four factors which impede the person's capability to be healthy when epilepsy is not stabilized:

1) The damage that seizures do to the brain due to the kindling effect[732]
2) The bodily risk to oneself and others when the seizures occur
3) The risk of sudden death (SUDEP)
4) The link between seizures and psychological and behavioral problems, learning difficulties, fatigue, and memory loss

From a biomedical perspective, seizures are dangerous as they lead to additional risks, damages, behavioral problems, and even sudden death. From a social perspective, they are dangerous as well, as they cause fatigue and memory loss, impacting the *capability sets* of our patients. Non-stabilization of seizures can also mean limited educational and work opportunities (due to the cognitive difficulties caused by seizures). It can also mean restrictions on activities (swimming, driving…) and limitations in social relationships (due to considerable fatigue after a seizure occurs…). Because of all of these risks, the main objective of medical treatment for epilepsy is to try to stop seizures before they occur. Stabilizing epilepsy from the biomedical perspective helps the person to be in

[732] Kindling is a metaphor which shows that the increase in seizures is similar to the way burning twigs can produce a large fire. A small seizure (or any seizure for that matter) can increase the likelihood that more seizures will occur. See: Bertram, E., 2007. *The Relevance of Kindling for Human Epilepsy*. Epilepsia 48.

good health because it reduces these risks. This idea is also in keeping with the patient's perspective, most of the time.

However, we will now need to take into consideration the third conception of being healthy, which patients defined as their capability to be agents. While we use the capabilities language here, patients defined their abilities to be agents in a variety of ways. This included finding a workplace suitable to them, engaging in a loving relationship with friends or with their partner, or through artistic projects such as writing. Indeed, the easiest way to understand the patient's conception is to consider its opposite: the impossibility to make plans or find satisfying relationships due to their disease. Patients interviewed wanted to stop or reduce their seizures because not stopping them meant that they could not plan their life projects.

As we can see from these definitions, patients were interested in their opportunities. However, their disease often stopped them from these opportunities. Notably when patients could not gain a certain amount of control of their epilepsy, this also affected their capability of practical reason (to be the designers and makers of their lives). For instance, several patients interviewed said they were waiting to stabilize their epilepsy to be able to plan what they considered "real" projects, such as working. This does not mean that they were unable to form a conception of the good: on the contrary, they had very specific goals and dreams; however, without seizure stabilization, they put their lives on hold. Here Nordenfelt's idea of health as adaptability becomes relevant to help these patients see themselves as agents even if they are unable to ever be completely healthy due to the non-stabilization of their seizures. We will return to this point in a later section.

The Trade-off between Medication and Seizures

So far we have understood that it is the patient's ambition to try to stabilize epilepsy to the greatest extent possible, because seizure activity does not allow them to be healthy. However, we will now need to consider the trade-off between medication and seizures. This is an important to consider because patients in our research project described the medication they were taking as *dangerous*. They identified the in-capability to be in good health due to the side effects of medication on their bodies, such as weight changes or the cognitive difficulties resulting from these medications. They described that these

medications made them feel "tired" "fatter" "thinner" "dizzy" "more forgetful" or even "suicidal" and caused considerable long-term damage to their bodies.[733]

Here the patient's perspective will help us move forward with the nuance of whether to completely stop seizures (the main goal of treatment) with these heavy medications. What the capability approach can bring to this discussion is that the focus for patients is to be able to use their *capability sets*. According to patients, if the side effects of medication are "horrible," seizures are even "more horrible" due to the considerable risk during the seizure itself as well as the long recovery time after seizures. The seizure itself was disabling for patients as it made them lose all capacity for agency. It was for this reason that most patients said they were willing to accept the side effects of the anti-epileptic medication — if effective in stopping or reducing seizures — in spite of their considerable side effects.[734] As long as the side effects did not affect their ability to use their *capability set*, it was a trade-off that they were willing to make. Nonetheless, it remains a tragic one.

From the biomedical perspective, we can understand why some doctors prioritize using any or even every means to stop seizures to help patients to be healthy. Most of the time, this will reflect the patient's priorities. However, what we can retain from our discussion is that the trade-off was too great when the medication stops them from doing what they want *to be and to do* in their lives. From a CA and from our patients' perspective, the right treatment is therefore not always the treatment which only stabilizes seizures; it is also the one in which the patient will be able to strive. Therefore the end goal of the treatment plan is now clarified: we are seeking treatment plans that enable patients to exert agency, even if does not mean optimal treatment results in terms of reduced seizure activity. Although this is still a tragic situation for the patient, it is one that may be *acceptable* to the patient and their family when trade-offs must be found.

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[733] According to the biomedical view, the long-term side-effects of anti-epileptic medication include chronic, cumulative dose effects; late idiosyncratic effects; late, dose-related effects; and delayed, teratogenic or neurodevelopmental effects. See: Gaitatzis, A., Sander, J.W., 2013. *The Long-Term Safety of Antiepileptic Drugs*. CNS Drugs 27, 435–455.

[734] This finding concurs with previous empirical research in epilepsy which shows that while patients appreciate that AEDs reduce seizures, their impact on their lives remains a major concern. See for example: Fisher, R.S., Vickrey, B.G., Gibson, P., Hermann, B., Penovich, P., Scherer, A., Walker, S., 2000. *The impact of epilepsy from the patient's perspective II: views about therapy and health care*. Epilepsy Research 41, p. 60.

The Emphasis in Patient Narratives

Before moving on to the next capability, we would like to introduce one more element owing to our reconstruction of our interviews into narrative case studies. As discussed in Chapter 2, the interest in reconstructing these patient narratives was to determine what was important for patients in relation their healthcare and beyond.[735] The first surprise of the research was that, rather than discussing their epilepsy treatment, their relationship with their doctor, the side effects, etc. (the medical narrative), patients like Christophe almost immediately emphasized their social difficulties of living with epilepsy. However, in Christophe's case, while his narrative started from a low point (his "situation of chaos," his in-capability of affiliation), it then went on to a higher point, the capability to work in an adapted workplace. His narrative therefore described a process of elaboration to arrive at his *capability set*.

Other patients started their narrative using a linear approach, in which they first described the way the disease was discovered. However, after this discovery, the narrative often jumped to the present day. In their storytelling, I was often confused about how their epilepsy had evolved and impacted their lives. Therefore I probed with questions specifically related to the evolution of their epilepsy to fully understand how their epilepsy had impacted them. However, once again, patients responded most of the time by telling me about the *impact* of their seizures in terms of the events in their lives, rather than the number or severity of seizures they were experiencing. In other words, their narratives were focused on what they *could* or *could not do* because of these seizures rather than on their severity or reoccurrence. What this *narrative emphasis* seems to confirm is the capabilities hypothesis that our patients are most interested in their opportunities.

This may seem an obvious point, but it is important to highlight as it is different from what the doctor seeks when they see patients in consultation. What interests doctors in their evaluation of the efficacy of the healthcare plan for epilepsy is the quantity and severity of seizures. Questions directed toward the patient and their families during the consultation have this aim in mind. However, what interests the patients is what their seizures prevented them from *planning* and *doing* in this temporality. Therefore what we can retain from this narrative emphasis is that for these patients, being in good health is

[735] I did not seek to categorize these narratives according to Frank's demarcation of restitution, chaos, or quest narratives, as the research ambition was wider (to understand what patients were interested in relating to me when telling their stories about epilepsy). We could however, following the capabilities approach, call several of these cases – such as Christophe's – a narrative toward a capability set.

partly linked to disease management under the biomedical model, but it is also connected to their overall lives — and relationships — and emotions — they experience in living with their disease. The narrative emphasis of these cases adds further weight to the pertinence of the patient's idea of being in good health as possessing and being able to use their *capability sets*.

Based upon these contributions from patients, we propose a threshold of being healthy for these patients as being able to *strive toward their life projects*. By this, we also take into account striving in adaptation. This proposal may not be an ideal situation for many (who will continue to dream of curing their epilepsy or of being fully capable of pursuing their dreams, which the disease does not allow them to do), but it may be an *acceptable* compromise for the healthcare provider, for the patient, and for the family when the healthcare plan is not able to achieve full seizure stabilization. In turn, given that patients see at least part of being healthy as tied to being able to pursue their life projects, it also gives them a means to exert agency when other solutions have failed.

3.4.2. Practical Reason

Now let us move on to discussion of practical reason with the help of our patients. Nussbaum defines practical reason in the capability list as, *"being able to form a conception of the good and to engage in critical reflection about the planning of one's life."*[736] For Nussbaum, practical reason helps us to reflect on our values, as well as to choose and order our functionings.[737] As she expresses it, our capability for practical reason seeks to empower us as *designers* and *makers* of our lives.[738] With the capability of practical reason, we already come to see patients as capable beings who can exercise choices about their lives. However in line with the capabilities' focus on affiliation, it means planning one's life, not in complete independence, but in relationships of sharing and reciprocity with others.[739]

Our purpose in using practical reason here as an epistemic tool will be to clarify the means through which patients seek to plan their lives with their diseases. We propose to investigate this subject through the differing types of knowledge that patients acquire about their disease and why they might be interested in acquiring it. If we were to focus (only) on the biomedical model of disease treatment, we might only be interested in the patient's knowledge as a way to increase health outcomes from the standpoint of seizure reduction. With the capability of practical reason, however, we have widened our focus to what this knowledge may bring to our patients' capabilities as agents.

Experiential, Testimonial, and Medical knowledge

The patients interviewed at the Teppe often have severe forms of epilepsy, frequent and severe seizures coupled with behavioral, psychological, and sometimes even learning development problems that have prevented them from attending regular schooling and integrating non-protected workspaces. They face considerable difficulties in developing a *capability set* that will enable them to plan their lives. However, as Martha Nussbaum has powerfully advocated, that does not mean that these patients are incapable of practical

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[736] Nussbaum, M.C., 2011. *Creating capabilities the human development approach*. Orient Blackswan, New Delhi. p. 34.
[737] *Ibid.*, p. 39.
[738] Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 284-285.
[739] She expresses this as, *"to plan for one's own life without being able to do so in complex forms of discourse, concern, and reciprocity with other human beings is, again, to behave in an incompletely human way." Ibid.*, p. 82.

reason. On the contrary, these patients actively seek to plan their lives, even with a reduced capability set. One of our patients' means to do so is to acquire knowledge about their disease. This knowledge was diverse and varied from patient to patient, but the patients interviewed[740] expressed some mix of knowledge from the following list:

Table 11: Patient Knowledge of Epilepsy

Description	Source of Knowledge
Type of epilepsy	Medical
Cause of epilepsy	Medical; testimonial; experiential
Temporality of seizure	Testimonial (usually family member)
Chronic nature of epilepsy	Medical; experiential
Trigger factors[741]	Medical; testimonial; experiential
Evolution of epilepsy	Medical; testimonial; experiential
Treatments and side-effects	Medical; testimonial; experiential
Risks	Medical; testimonial; experiential

As we can see from this list, this knowledge was a mix of experiential, testimonial, and medical knowledge. What we mean by medical knowledge is the knowledge about their disease either given or requested from the healthcare provider; while testimonial knowledge is information that is transmitted by testimony (usually family members).[742] We define experiential knowledge as truth learned from personal experience with a phenomenon.[743] Experiential knowledge has several features: it is pragmatic, orientated to the present, and holistic.[744] While this type of knowledge is distinguished as coming from personal experience, it often exists concurrently with medical knowledge or information gained through other sources[745] (such as testimony from family members). As we can see

[740] Here we are not proposing that all patients at the Teppe have this knowledge; our research population does not necessarily reflect the 400+ patients at the Teppe. However, given that research participants came from three different services, including a medical home, a variety of types of epilepsy were taken into account.
[741] This refers to individual factors (such as stress, drinking, emotions, etc.) which may "trigger" seizures. While there are some commonalities among trigger factors, most patients had to acquire self-knowledge of which trigger factors are specific to their individual epilepsy.
[742] Both types of knowledge are of course testimonial; however, we wished to distinguish here between the two different sources of knowledge, such as those given by the doctor and the information transmitted by family members.
[743] Borkman, T., 1976. *Experiential Knowledge: A New Concept for the Analysis of Self-Help Groups*. Social Service Review p. 445.
[744] Pragmatic in that it is orientated to results that work; orientated to here and now action; and holistic in that takes into account the total phenomenon experienced. *Ibid.*, p. 449-450.
[745] *Ibid.*, p. 448.

from our patient contributions, the various sources of patients' knowledge about their disease is often mixed together. While some types of knowledge were gained directly from the medical consultation and closely resembled (although often not with the same vocabulary) medical knowledge of the disease, this knowledge was also influenced and expanded by testimonial knowledge (usually from family members who witnessed their seizures) and their own experiential knowledge about their disease. For instance, the chronic nature of their epilepsy was often learned in the consultation room, when the doctor informed them about this aspect of their disease. However patients fully appropriated this knowledge when they experienced this chronicity in their lives. This experiential knowledge was pragmatic and orientated to the effect it had on *planning* their lives. For patients who were able to accept this chronicity, this knowledge could become a facilitating rather than disabling factor, as it allowed them to adapt their life projects to the limitations imposed by the disease.

As Nordenfelt has suggested with his concept of adaptability, acceptance of this chronicity enabled some patients to re-orientate their life projects, to *adapt* their life choices to the realities of their diseases. Both Melanie and Christophe have learned to adapt their career expectations to the limitations imposed by their disease. While they had never before imagined a career in carpentry or administration, the chronicity of their disease obliged them to adapt their life choices to their epilepsy. However, that does not mean they did not continue to strive. Both were able to find new work opportunities that they enjoyed. Therefore what we can see from the patient's perspective is that our patients were interested in acquiring this knowledge(s) about their disease because it was a facilitating factor. It enabled them to adapt and to be healthy because they could in turn use their *capability sets* in realistic ways to plan their lives.

The Cause of Epilepsy

We will now investigate one specific type of knowledge signaled by our patients, the *cause* of their disease. Understanding how patients appropriate knowledge of the cause of their disease will give us vital clues to understand how patients appropriate the knowledge of their disease in terms of their life projects but also in their relationships with their doctors. As highlighted by the table above, the cause of epilepsy was gained through medical, testimonial, or experiential knowledge, and often in some combination of the three. Some patients identified the cause as either a person or an event which triggered their seizures.[746] This knowledge was informed by others' (especially family member's) testimony. For instance, patients incorporated the testimony of a family member who related to them when or why their epilepsy occurred, for example a family's member's death or a medical error. An alternative was when a patient "self-discovered" a link between an emotional event (such as the loss of a grandparent) and the start of their epilepsy and made a correlation between this event, the person involved in this event, and their disease. The cause of their epilepsy was rarely based upon medical knowledge, as most epilepsies are idiopathic in the biomedical model.[747]

However, even when the self-discovered or family-discovered cause was negated by the healthcare professional, the experiential and/or testimonial knowledge of the cause was often maintained by the patient. The cause was of great interest to patients. It gave their disease meaning in terms of their life projects and in their relationships with others. It also had an effect on planning their lives. Indeed as the cause was often linked to pivotal moments, such as events and persons in the patient's life, knowledge of the cause took on meaning in planning their life projects and the persons that would be involved in these projects.

Although the cause was viewed as important knowledge by patients in order to appropriate their disease, this information was not prioritized by healthcare providers (and

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[746] Compared to the etiology used in seizure classifications which says that the cause of epilepsy is structural, genetic, infectious, metabolic, immune, or unknown. For more information, see: Scheffer, I.E., Berkovic, S., Capovilla, G., Connolly, M.B., French, J., Guilhoto, L., Hirsch, E., Jain, S., Mathern, G.W., Moshé, S.L., Nordli, D.R., Perucca, E., Tomson, T., Wiebe, S., Zhang, Y.-H., Zuberi, S.M., 2017. *ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology.* Epilepsia 58, p. 515.

[747] Kammerman, S., 2001. *Seizure disorders: Part 1. Classification and diagnosis. Western Journal of Medicine* 175.

was largely considered irrelevant), unless it helped define or modify a treatment plan.[748] As the cause of the epilepsy had an uncertain place in the treatment plan, it was often excluded by patients in discussions with doctors. However, most patients started our interview by relating to me the cause of their epilepsy. What the narrative emphasis of these interviews suggests is that elements such as the cause that are not necessarily related to the treatment plan or biomedical understandings of the disease remain important for patients in planning their lives.

Gaining Control

We have so far understood that patients seek to gain knowledge about their disease in order to be able to adapt their life projects to the constraints of the disease. However, gaining knowledge is also a means of gaining control of their seizures.[749] Patients "experimented" "observed" "noticed" in what situations their seizures occurred, due to circumstances or people or emotions and gained experiential knowledge of how to exercise control of their seizures through these observations. In one patient autobiography, this was expressed as, *"this epilepsy that each person can make their own, in order to dominate or tame it…"*[750] While this kind of experimentation was encouraged by the healthcare team, it was above all at the individual patient's initiative. Because of this, the results of this exploration were not necessarily shared with healthcare providers. One patient for instance claimed that for him "sport was a medication." Despite this medical wording, he was surprised when I asked him if he shared this information with his doctor.

From the perspective of these patients, and in contrast to the biopsychosocial model, we can see that from the patient's perspective that this information will not necessarily need to be shared with their doctor, as it is linked to the person's capability to find ways to take control independently of medical expertise. If we require that patients tell this knowledge to their healthcare provider, we are after all just providing another means for this information to be filtered through medical expertise. From the perspective of the patient, this is not desirable, as their experiential knowledge helped them to reduce their

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[748] For instance if the cause was infectious. If the cause was undetermined or was not likely to impact the diagnosis or the care plan, however, it was not considered useful information in the treatment plan.

[749] Thus the patients' motivations for acquiring knowledge correlate with the Ottawa Charter, which states that, *"people cannot achieve their fullest health potential unless they are able to take control of those things which determine their health."* Health Organisation, 1986. *Ottawa Charter for Health Promotion*. p. 1.

[750] Our translation. Plaussu, J.-R., Gouttenoire, J.-P., 2013. *Epileptique ... et alors?* Chronique sociale, Lyon. p. 13.

dependence on others. Thus we have resolved one issue present in our discussion from Chapter 1. If the patients interviewed in this research project decided to share this experimental knowledge with the doctor, it was when they believed that it could have an impact on the treatment plan. Thus for patients, we can see that not sharing this kind of experiential knowledge only becomes problematic when a patient desires to share this information but is stopped by fear (or some other concern). Otherwise we can consider from the patient's perspective that this knowledge may be in her private domain, given that it is an important means to gain control of the disease.

Experimental knowledge was also linked to the capability of patients to live *with* and *toward* others (the capability of affiliation). A clear example of this is patients' conceptions of gaining control of behavioral problems.[751] Some patients were particularly anxious about being able to gain control of certain aspects of their behavior in order to envisage an *active life* and to be able to enjoy *durable relationships* with others. This was also seen as a way to stabilize their epilepsy and to be healthy. For instance, a patient described part of his stabilization as being able to find a solution for his behavioral problems. He was glad to have found a way that "controlled him" given his history of violence, which he described as a loss of control of himself and others. His ability to stabilize his behavioral problems also created an opportunity for him to be able to form and maintain durable relationships with others. He is now in a stable relationship with another patient, planning his career, and also has become a leader among patients in the service thanks to this control.

To summarize this discussion, patients were motivated to learn about their disease because it helped them to adapt to and gain control of their diseases. These facilitating factors in turn gave them more opportunities to plan their lives, to use their *capability sets*, and in particular their capability of practical reason, to design and plan their lives. While this was often related to seizure stabilization for individual patients, it did not necessarily relate specifically to the treatment plan and often remained in the private domain of our patients.

[751] Behavioral problems are recurrent in epilepsy due to frustration over the unpredictability and consequences of seizures, but also because seizures and their medications can cause behavioral changes.

Gaps in the capability set

All in all, these various types of knowledge were acquired by patients through a long and difficult journey in the healthcare system, from generalist to specialist, and at times, to residence at live-in healthcare institutions. The disease has affected patients' lives not only in terms of their treatment, but also in terms of developing their overall *capability sets*. These particular patients often had to stop their schooling at a young age, or could not work, due to their diseases. Thus they experienced an in-capability to pursue their life projects not only because of the non-stabilization of their disease, but also because of overall gaps in their *capability sets*. For patients to be designers and makers of their own lives, they needed to be able to develop a full range of capabilities, which in these particular cases the disease did not allow them to develop to a threshold level. In turn, when one capability was missing, it meant a capability failure for themselves overall as agents, as Martha Nussbaum has suggested.

Here we can see the full potential of Nussbaum's call to help these particularly difficult cases. As we have advocated in our discussion of the strength of the capabilities approach over existing empowerment approaches, understanding these difficulties as capabilities failures is not a call for passivity. With a capabilities perspective, institutions will prioritize helping these patients – indeed all patients – to develop their *capability sets*. This is not necessarily a responsibility to be "dumped" onto the doctor's shoulders, but will require diverse capability sets coming from diverse professionals. In the case of our patients, specific professions (such as social educators) help patients explore and develop these *capability sets*, including moving them beyond their fears of failure.

Therefore from these patient contributions, we can understand that the capability of practical reason helps our patients to plan their lives, as part of a wider *capability set*. Practical reason is, as Nussbaum has stated, an architectonic capability, present and interconnected with other capabilities including health, emotion, and affiliation, and will need to be stimulated in order to facilitate the patient's overall capabilities. These capabilities will in turn be nourished through affiliation with others. It is not only a question of planning our lives with others, as Nussbaum has suggested, but it is also possible that others can help us *see* capabilities that we ourselves ignore and encourage us toward new opportunities. Therefore let us now turn to the final capability to be explored, affiliation.

3.4.3. Affiliation

"We speak together. We speak together before taking a decision."

— A patient at the Teppe

"It's not the doctor who is director of the disease. The doctor, he is only there to be a counsel, to help, but in daily life, it's the patient who is going to act in his daily life…we can say all we want, in the end, it's the patient who decides."

— A doctor at the Teppe

We have so far explored what it means for patients to be healthy and how finding a means to gain control helps them to become *designers* and *makers* of their lives. In this section, we will investigate Nussbaum's capability of affiliation, which is linked to persons as social beings. As highlighted by our previous discussion, this capability involves several things. In the first place, it involves being able to live *with* and *toward* others. In Nussbaum's approach, all persons are included in this capability, not only those who may be considered "apt" in workplaces or healthcare environments. In the context of healthcare, therefore, we can already envisage situations in which patients may receive assistance, but also that they can also bring their own contributions. This assistance could be in terms of providing relevant information to help the doctor in the treatment plan; however, it could also mean actively helping doctors with their practice. The capability of affiliation will therefore help us unravel one of the difficulties identified in Chapter 1, namely why doctors should prioritize patient empowerment due to its considerable time investment.

The second part of Nussbaum's capability of affiliation seeks to secure self-respect and non-humiliation for all persons. Policy directed with the capabilities approach will be focused on helping societies as a whole to ensure that all persons are treated as dignified beings of equal worth. As highlighted in our discussion, public policy designed with the capability of affiliation in mind goes beyond just laws that can guarantee certain rights. It engages a wider idea of relationships which affects whether or not these rights can be exercised in practice (the combined capabilities). Nussbaum recognizes that we all live in a wide circle of social relationships and that affiliation can either be fundamentally facilitating or corrosive. In Chapter 2, we investigated how the emotion of fear has impeded the PWE's ability to live *with* and *toward* others, including their capability to be

treated as a dignified being worthy of respect by others. This already suggests to us to the salience of Nussbaum's capability for patients to be able to live well with their diseases.

In both our explorations of being healthy and practical reason, we saw a considerable role for others in helping our patients develop their capabilities. As we have elaborated in Chapter 1, some existing patient empowerment definitions seek to build the capacity for patients to "manage" their disease as autonomously as possible. We have already discussed the risk of defining patient empowerment in these terms. By focusing on affiliation as the CA enables us to do, the relational aspect of empowerment is now fully taken into consideration. In the discussion that follows, and in order to avoid the many facets of affiliation, we will here focus on two important relationships for patients at the Teppe: the doctor-patient relationship and the patient-to-patient relationship. As a first step, and in order to demarcate our patients' perspectives from existing patient empowerment approaches, we will solicit the patient's perspectives on autonomy.

Patient Conceptions of Autonomy

To remind our readers, our research for this part of the thesis took place in a site which could be called "borderline" as it was a site in which patients live full time. By necessity of living in residence in a healthcare institution, and under the constant supervision and care of a healthcare team, patients live in a space of reduced autonomy that is also stifled by institutional temporalities. This temporality gives them limited agency in planning their days. Patients at the Teppe often defined their autonomy as gaining or losing this agency. They talked about autonomy in terms of being able to take medication autonomously, i.e. without outside management by a nurse or other healthcare professional and in terms of capabilities to manage their daily life activities and social relationships both within and outside the service. For example, one patient, proud of his autonomy said, *"yes, I am in Autonomy 2*[752]*, which means I prepare and keep the medication in my room. I am autonomous."* He repeats several times during the interview that he is autonomous in terms of taking control of his medication, because this gives him control of his free time. In turn, not being able to make choices about their lives, due to rules or temporalities of the hospital, meant a loss of autonomy. A patient in same service who had to accept that the nurse gave him his medication (morning, noon, and night) said he was less autonomous, as

[752] This is vocabulary related to specific rules for medical-social institutions, which evaluate patients' capacities for autonomy, allowing for reduced or increased autonomy in preparing and taking medications. The patient here is taking on the vocabulary of the institution.

he had to regulate his activities to that of the nurse. Other patients complained that they were unable to sustain their love relationships because of the temporalities of the institution, including a busy schedule of medication, workshop, and meal planning. What we can retain from these patient definitions of autonomy was their focus on their opportunities, including in affiliation with others, with which the hospital environment and temporalities often interfered. As we have discussed, current definitions of empowerment that focus on increasing autonomy of the individual patient have often failed to take this environmental view. Patients here help us retain the importance of the facilitating environment in the exercise of choices.

The Doctor-Patient Relationship

Keeping in mind this aspect of the facilitating environment in helping patients exert agency, we will now examine what kind of participation patients seek in the consultation. As we have already seen in our discussion of health, the end goal of treatment for patients is to find a way to stabilize their epilepsy, but without interfering with their life projects. Therefore the doctor-patient relationship was one in which was either facilitating or corrosive. Our patients said they needed three main things from doctors during the consultation in order to work toward a treatment plan:

Table 12: What Patients are Seeking in the Doctor-Patient Relationship

Needs	Patient conceptions
1. Being treated as a person	Being treated with respect by the healthcare provider, including recognition that the patient is the most qualified to make life decisions
2. Having a say in treatment decisions	The decision to stop or start medication and other treatments made together with the doctor and the family; possibility to propose a new treatment or treatment modifications
3. Possibility to bring knowledge to the encounter	Bringing specific information on their individual epilepsy and side effects of medications (or other technical solutions) to help decide the treatment plan

The first element that patients identified as important was being treated as a person. Here we will rely on the patient's definition of being treated as a person: patients identified being treated with respect by their healthcare provider, especially by recognizing that the patient had the right to participate in decisions about the treatment plan, and that the patient was the most qualified in making decisions about their lives. In other words, patients

wanted to be treated as agents, with their own ends to be achieved. This may seem an obvious point, but as epilepsy includes restrictions on activities (swimming, driving, certain professions), the advice, recommendations, and even legal requirements tasked to healthcare professionals treating epilepsy will also affect patient's projects outside of the treatment plan. Patients gave a clear message that while this information helped them, in the end it was they who decided what to do with this information[753] (as the doctor's quote at the beginning of this section noted).

When this first need was met, patients were also able to move toward the second and third needs identified, which included having a say in treatment decisions and bringing their own knowledge to the encounter. Patients who described the capability to do these things with their doctors described agency in the doctor-patient relationship, for instance: "*We speak together. We speak together before taking a decision. The doctor is going to prescribe me a medication, he is going to ask me what I think, and I will respond."* However for those who described a conflictual relationship with their healthcare provider, or who said they were incapable of making decisions, a passive vocabulary was used: "*Actually it's him (the doctor) that chooses the medication…its them that takes care of it…it's them who chooses…it's not for me to choose."*

Whether or not the relationship was participatory, the consultation was understood by the patient in relational terms. However, when it came to deciding and planning their lives, patients were seeking autonomy above all. Patients who sought some form of collaboration or agency in the doctor-patient relationship in turn did so because healthcare decisions affected their lives, their capability to plan their projects, and in turn how autonomous they could be in searching for it. Assistance from healthcare providers was therefore sought as a means to help them *gain control* of their disease once they left the doctor's office. We therefore propose that for patients, being empowered in the doctor-patient relationship means *being capable of working in collaboration with the healthcare provider and/or her family to help define an acceptable healthcare plan.* The difference from Biomedical Claim 3 in the definition we propose is in the word "capable": we assume that the patient, the doctor and the institution will need to ensure that this capability can be used in the real-world environment of the consultation. Although we retain the idea of both

[753] Although patients can generally choose what to do with this information, doctors do retain a certain control due to risk. Doctors for instance are tasked with "clearing" epilepsy patients for driving after a period of time in which they are "seizure free." Thus their involvement in patient's lives is sometimes beyond the treatment plan.

parties working together to define an acceptable treatment plan, we favor the term "acceptable" over "personalized" to ensure that the treatment plan is the one that enables the patient to continue striving toward their life projects. A personalized treatment plan, is after all, not a guarantee of acceptance (and in turn, of adherence).

Conditions for Participation

Given the importance of the treatment plan to enable patients to pursue their life projects, patient participation in the healthcare relationship was important for most of the patients we interviewed. Following Entwistle's analysis, we see patient participation in decision-making as not only limited to negating or agreeing to a specific treatment plan proposed by a doctor, but also as involving many stages of participation, including: *recognition and clarification of a problem, identification of potential solutions, appraisal of potential solutions, selecting a course of action, implementation, and evaluation of the solution adopted*.[754] This harmonizes with the patient's conceptions of being treated as a person in the relationship through possible functionings such being able to make decisions on stopping, starting, or proposing a new treatment and/or bringing experiential knowledge into the encounter (should they wish). However, the level of participation for our patients differed based upon their capabilities to participate (due to their *capability set*) as well as their facilitating environment (their *combined capabilities*).

Doctors in particular identified some barriers to patient participation due to gaps in the patient's overall *capability set*. They notably asked patients to have a certain level of aptitude to be able to participate actively in the doctor-patient relationship. Doctors expressed this as a need for *argumented choices*. What they meant by this phrasing is that patients had critically reflected on the reasons for their healthcare choices and that they were able to defend their opinion or preference to the doctor. For instance, if patients showed a preference for certain medication timing, it was accepted if they could argue why this timing was important for them. In Melanie's case, it was easier for her to be able to plan her day if heavy doses of her medication were not given at night; this kind of *argumented choice* was accepted by healthcare providers. This raises, of course, a certain problem, as the person to decide whether or not these choices were "argumented" is the healthcare provider.

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[754] Entwistle, V.A., Watt, I.S., 2006. *Patient involvement in treatment decision-making: The case for a broader conceptual framework.* Patient Education and Counseling 63, p. 274.

From patients' perspectives, however, their barriers of participation were tied more directly to their *freedom* to exercise this capability in the consultation. If we see this through the lens of the capabilities language, we can see that as a precondition for participation, doctors requested that patients already possessed a threshold *capability set*, notably a threshold of practical reason, to be able to participate in designing the treatment plan. However, patients and doctors' assessment of this capability often differed. Some patients for instance described problematic relationships with doctors because when they proposed *argumented choices*, these choices were not seen as argumented by the healthcare provider.

We do not here wish to make a judgment on this problem of "aptitude" so hotly debated in bioethics. However, the differing perspective of the patient and the doctor has given us an important component for our patient life empowerment approach. In the first place, patients have shown that it is not enough to acquire a capability, but that they will also need to be able to use it in the consultation (their combined capabilities). We can also understand the critique coming from healthcare providers that, in order to do no harm, patients will need a certain capability to express *argumented choices*. If we require this from patients, we can therefore explore how doctors (or other healthcare professionals or families) can help support our patients to develop practical reason. We do not advocate this solution to "get doctors off the hook" (thus putting all responsibility on patients), but rather to envisage a feasible means to enable greater patient participation in the consultation without conflicting with healthcare providers' professional obligations.

The Incoherence of Adherence: the Patient's Perspective

One final element will be explored from the patient's perspective of the doctor-patient relationship: treatment adherence. As the biomedical claims to patient empowerment are based on an end goal of better treatment outcomes through adherence, it will be important to understand patients' views of adherence and whether this may be linked to patient's definitions of patient empowerment.

In the first place, in terms of adherence to treatment, the patients interviewed at the Teppe, linked to their long and often difficult healthcare journey, did not directly link adherence with being empowered. In other words, the last assumption of the biomedical model, that the final — and most important — end goal of patient empowerment will be adherence, has limited meaning for patients themselves. This is fairly intuitive, given that merely taking a medication as prescribed does not place the patient in her full capacity as

an agent. However, even if patients did not link adherence with empowerment, taking their treatment as prescribed was taken very seriously by all the patients interviewed at the Teppe. They understood the (possible) link between medical adherence and the possibility of reducing seizures. They also had experienced the risk of non-adherence to medication by having seizures. Not adhering to their medication was even a source of shame for some patients. Thomas for instance said that, *"there was just one time where…one morning, I was doing an internship, I was really late, and I forgot to take my medication…when I came back to my house in the evening, I had a seizure, because I had forgotten the morning dose."* Thomas linked his seizure destabilization to his imperfect adherence. He went as far as to repeat several times during this interview that it was his "fault" that the seizure came because of this forgetfulness.

While we could now say that we have successfully "responsabilized" this patient to take their medication as prescribed, this is not the whole story. For patients like Thomas, adherence was important to him because he had a seizure, impacting his capability to plan his leisure time. If what matters for patients in adherence is the overall context of being able to plan their lives, then adherence may not be their priority if they do not identify a link with their seizures. For those whose treatment plan is facilitating, however, adherence is their personal concern. When Thomas experienced a seizure, he took extra care not to miss the next dose. He did not do so because he was afraid of being blamed by the doctor, or because he was told to adhere: he did so because seizure activity meant not being healthy, an in-capability *to be* and *to do*. Therefore from the capabilities perspective, we cannot punish the patient for not following the doctor's orders or for failing to adhere. Our social responsibility will be to do our best to help them to be empowered, as they are willing and capable of doing so. It is still likely that adherence will be an important component of the healthcare plan, but giving the ultimate decision-making power to the patient puts the responsibility on both the doctor and the patient to ensure that the healthcare plan is acceptable to the patient.

Patient-to-Patient Affiliation

Now that we have explored the doctor-patient relationship and its barriers to help patients become empowered, in this final section we will show the full potentiality of patient-to-patient reciprocity.[755] The patients interviewed in this research project are not at Nussbaum's desired threshold level of capability; however, that does not mean that the social relationships in which they engage do not help themselves and others to be empowered. Patients defined empowerment *for* other patients in the following ways: 1) bringing expertise on disease and treatment to other patients; 2) participating in experimental research to help other patients and doctors; 3) being a source of support for other patients.

One of the ways patients helped each other was by giving advice on epilepsy and treatments to other patients. Patients identified both receiving and giving this information as a way to better understand and live with their disease. This patient-to-patient reciprocity also took the form of social integration. Patients said that they helped other patients to integrate into the hospital service, or that other patients did so for them. This helped them overcome their fear of others and of the hospital, in turn helping them to be healthy. One patient even described this affiliation as a way to reduce her seizures. She said that, *"yes (I have less seizures now), it's the fact that I've found friends here."*

For patients, being empowered also means the *capability to assist other patients*. This suggests that patient empowerment should be understood in terms of the ability to live *with* and *toward* others in order to realize its full potential of the concept from the patient's perspective. The patient's way to be empowered and to exert agency is not just as a passive receiver of assistance, should it be from the doctor or the family; it also means exerting agency through helping others. Patients' abilities to contribute to society are not just as *receivers* of care, but also as active *givers* of care for other patients in ways that *only they* are capable of doing because of the shared connection of their disease. Nussbaum's capability approach and our patients therefore show us the full potential of *mixophilia*, of the benefits that come from seeing persons, even those in situations of severe disability, as

[755] We have preferred the wording of capabilities for development of our concept over the formulations of care such as proposed by Tronto. We argue that patients are not only "receivers of care" (Tronto's final phase of caring), but also active agents in giving and receiving care. While Tronto would not necessarily disagree with this claim, the capabilities approach explicitly advocates for the individual's agency within the capability of affiliation. For more information on Tronto's phases of care, see: Tronto, J.C., 1993. *Moral boundaries: a political argument for an ethic of care.* Routledge, New York. p. 107-108.

active and creative beings, receiving, but also helping others to live well because of their common experiences of disease.

3.5.4. Preliminary Conclusion

Through our method *with* capabilities, we have come to understand that patients are interested in participating in healthcare decision making as a means of gaining control of their lives. We have also seen the importance for our patients to live *with* and *toward* others in meaningful relationships. When looking at the patient life empowerment approach from the patient's point of view, we can see that we will need to guarantee *empowering relationships*, with the doctor, the family, and society in order to help the patient to live well with their disease. The table below summarizes our discussion thus far:

Table 13: Capabilities for a Patient Developed Approach

Capability	Conception	Means to achieve
Being healthy	Being able to make and design life projects	Finding ways to control disease; finding an acceptable treatment plan
Practical Reason	Elaboration of choices and desires	Learning about the body/disease
		Learning about capabilities/limits
		Developing practical reason to make and design lives
Affiliation	Working with others to elaborate acceptable treatment plans and life projects	Facilitating relationships with the healthcare provider; spaces and temporalities for patient-to-patient sharing

We have now identified several components necessary for our proposal, which we will outline here before proposing our patient life empowerment approach.

1) In the first place, the priority of patients is to be able to develop and take advantage of opportunities to plan their lives. Placing the emphasis on the patient-doctor relationship is not sufficient to encompass patients' reasons for being empowered *for* their lives and *in* their environments. Thus patient empowerment needs the additional word "life" into its configuration.

2) In the second place, we can understand that the most important aspect for patients in their treatment is to be healthy and/or to learn about their diseases in order to "take" or to "retake" an active part in their life decisions. *Gaining control* of their diseases concretely means the possibility of being able to make treatment and other life decisions, but also to find their own ways and means of living well with their disease. This means that healthcare plans and other policies should go toward stimulating agency in our patients.

3) In the third place, since we can flourish with the help of others, we will place considerable responsibility on others (public policy but also other relationships in the patient's life) to help our patients work toward empowerment. As we have seen in our chapter on fear, patients are unhealthy in society and will need various kinds social support to be able to live *with* and *toward* others. We will therefore call for a wider social responsibility for family members, healthcare providers, and society as a whole.

4) In the fourth place, Nussbaum's idea of a threshold remains a pertinent way for us to define both a realistic cadre and to take into consideration those for whom reaching the threshold will already be a considerable task. Keeping in mind this threshold is also a way to avoid putting excess responsibility on patients to perform and instead moves us toward a more realistic goal in helping our patients to be supported to the level in which they are capable. However the idea of a threshold also sets the bar high enough to envisage social support for those with considerable difficulties moving toward it. We therefore propose in line with patient contributions that patient life empowerment has been achieved when the patient *is able to develop and make their life choices, including in the treatment plan, with help as needed from the doctor, with their families, and with other patients*. Now let us outline our approach and its implications for our institutions.

3.5. Patient Life Empowerment

Now that we have solicited patient and healthcare provider contributions, we will propose our patient life empowerment approach. We will not call our theory an "ideal theory" even though our approach will be a demanding political task for healthcare and other institutions today. As our approach has started from a non-ideal theory methodologies (Fricker's failure-first methodology), it has sought to practically identify the ways and means for patients to live better with their diseases. It thus retains the aspects of non-ideal theories that seek to make comparisons and evaluations to guide policy change. While we argue that the patient life empowerment approach may be the "means to achieve" a certain ideal, we wish to retain the critique inherent in non-ideal theories to understand how to work out such problems in practice. We will therefore call our approach, following Dworkin, an *approach for improvement*.[756]

Patient life empowerment approach: *a flexible and multi-purpose conceptual framework that seeks to help patients be empowered in their lives.*

The individuals and groups involved include all those who can help patients to live well with their diseases, including family members, healthcare professionals, other patients, workplaces, and wider society. Public policy in the PLE approach will be focused on developing laws and institutions which help patients develop their capabilities.

Patients will receive assistance in the development and use of their capabilities by actors and/or institutions, to the extent needed and desired by the patient. This assistance may include helping patients adapt their life projects due to the limitations that their disease imposes, providing adapted education facilities and workplaces, programming which helps family members to support the patient, providing a facilitating environment for healthcare providers to support the patient, etc.

In the healthcare consultation, the PLE approach will focus on helping patients and doctors work together to form an acceptable treatment plan for the patient. By acceptable, we mean a healthcare plan that allows patients to continue striving toward their life projects.

The PLE approach aims to provide empowering policies and relationships to help patients to be healthy to (at least) a threshold level. The threshold level of being healthy in the PLE approach is that in which patients are able to develop and make their life choices, including in the treatment plan, with help as needed from the doctor, with their families, and other patients.

[756] Robeyns, I., Department of Philosophy, Florida State University, 2008. *Ideal Theory in Theory and Practice: Social Theory and Practice* 34, p. 356. Quoting Dworkin in *Sovereign Virtue*, p. 147-166.

The patient life empowerment approach is thus a flexible and multi-purpose framework which invites us as a society, as healthcare providers, as workers, as policy makers, as employers, to think how to help patients flourish *with* and *toward* others in our diverse roles and interactions in society, including but not limited to social transformation. We therefore call our PLE model an "approach" rather than an outcome. The patient life empowerment approach is ongoing and the person will have different needs at different times and from different people. It is also an approach because it will take different forms for different people. The idea of "living well with disease" will mean different things for different people. The emphasis in our approach is to ensure that patients can seek their version of the good, with adaptation as necessary due to their disease and treatment.

We retain the idea of *capability* in our approach for several reasons. In the first place, it shows that patients are striving toward developing their *capability sets*, which will enable them to plan their lives. Secondly, the strong call in the capabilities approach for the facilitating environment shows us how much we need others not only to acquire but also to mobilize these capabilities. By taking into focus the environment, we are moving away from patient empowerment as an individual responsibility for the patient or for the doctor and instead engaging in a wider cadre of social responsibility to help patients to live well with their diseases. However, we are also changing the starting point of our vision of patients: we see them, with the help of the capabilities approach, as capable beings with their own desires and priorities, and not just as patients waiting for assistance.

We also retain Nussbaum's focus in the capabilities approach on capabilities vs. functioning. We emphasize the facilitating role that others can provide in helping patients toward their capabilities set. However, this does not give legitimacy for others to decide the content of our patients' life projects. We also recognize that some patients will not wish to make their own choices, even with the help of others, and may prefer a surrogate to take their place. We will not impose a paternalistic view on patients; it is up to them to decide what their need is or want in terms of affiliation, therefore we qualify our definition with the words *to the extent needed and desired* by the patient. In our definition, it will be up to the patient to decide their needs and desires, and what support they need (or do not need) from others. In taking on the term "need," we include those that need more assistance than others, but also in order to recognize how much all of us need others to flourish.

We do keep the word "patient" in our approach to emphasize that the person has needs related to the healthcare act; however, in our definition we emphasize that the patient is the person who acts in a wider cadre than just in their disease. Thus our approach

releases the strain on the doctor-patient relationship and helps us see that patient is empowered *with* and *for* their life choices, not just to achieve healthcare outcomes.

3.5.2. Implications for Institutions

> *"Individuals live and operate in a world of institutions. Our opportunities and prospects depend crucially on what institutions exist and how they function."*
>
> *Amartya Sen*[757]

In this section we will investigate what implications our approach may have for public policy. As Traynor has strongly argued, *"if health workers want to take the notion of empowerment seriously, there is no way to avoid asking radical questions about the functions of state agencies and their place within them."*[758] We will need to examine such state level policies to ensure that the patient life empowerment approach is not piecemeal or dependent on the desire of individuals. However, we will also see how this perspective may also be able to help transform individual medical practice.

Implications for Overall Society

In the first place, patient empowerment is no longer only on the shoulders of only the patient or on the doctor. Patient empowerment has become a wider social issue in which we are all involved in helping persons with chronic disease to live well in society. As the Ottawa Charter states, *"the prerequisites and prospects for health cannot be ensured by the health sector alone…health promotion demands coordinated action by all concerned: by governments, by health and other social and economic sectors, by nongovernmental and voluntary organizations, by local authorities, by industry and by the media. People in all walks of life are involved as individuals, families and communities."*[759]

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[757] Sen, A., 2001. *Development as freedom*. Oxford University Press, Oxford ; New York. p. 142.
[758] Traynor, M., 2003. *A brief history of empowerment: response to discussion with Julianne Cheek*. Primary Health Care Research and Development 4, p. 136.
[759] World Health Organisation, 1986. *Ottawa Charter for Health Promotion*. p. 2.

When we consider that the patient is empowered to plan and make life choices in *society*, not just in the healthcare relationship, we in turn need to look at what this society allows the patient to do. For instance, does society encourage the patient to be passive in their healthcare plan? Does the family overprotect the patient and take their place? Does society allow patients to enter the workplace, and once there is there any leeway for adaptation to allow them to flourish? In the patient life empowerment approach, we will need to imagine our institutions — healthcare but also others — as forums to stimulate patients' agency.

However, we concede that the patient life empowerment approach is demanding, and will require both individual and political will to make it happen. While it was not our intent to quantify the approach for our subject, we do encourage development of economic indicators as a fruitful exploration for future research, as the very real economic costs of marginalization for certain patients represents a considerable cost burden to governments due to under and unemployment. If quantitative indicators are developed with such a holistic vision of well-being as the patient life empowerment approach offers, it may help to justify such policies on the ground in our institutions, businesses, and schools. These indicators will need to show the healthcare costs of patients being unhealthy (living in an environment of fear for instance, leading to more seizures), and how these social, personal, and healthcare costs are related to the economic implications of under and unemployment of patients in the workplace. In addition, it will be necessary to quantify the patient life empowerment approach in its longevity. The existing biomedical model is largely a short-term approach focusing on adherence to the treatment plan and can be part, but not the only basis, of the patient life empowerment approach or understandings of such an approach for public policy.

As the patient life empowerment approach considers being healthy in a wider cadre involving more than healthcare institutions, it will involve support for adapted workplaces, family empowerment programs, and education programs to raise awareness on diseases which continue to haunt the popular imaginary. As Giraud *et al*. highlight[760], an important dimension of exclusion is socio-economic: a person without access to a job has little access to relational material networks. We may also add that they have limited epistemic contributions to offer to the world of work because of this exclusion. Facilitating access to

[760] Giraud, G., Renouard, Cc., L'Huillier, Hh., De la Martiniire, R., Sutter, C., 2013. *Relational Capability: A Multidimensional Approach.* SSRN Journal. p. 11.

the workplace and fostering workplaces that will allow our patients to participate fully as social beings will be an important means of empowering them.

Another important dimension of exclusion is social, including those who do not have close family, friends, or other social ties that allow them to participate as social beings in their communities. Working with families (or other persons close to the patient) or supporting new relationships such as patient-to-patient friendships will also be part of our approach to help our patients toward their flourishing. Giraud *et al.*, use these two criteria plus the capability of human decision making as the basis of their Relational Capability Index.[761] Such an index could be used to evaluate whether or not policy changes have allowed patients to be included into their wider networks.

Implications for Healthcare Institutions

With the help of the capabilities approach, we view patients as capable beings, who may decide to participate in the healthcare plans designed for them. We will therefore need to image a facilitating environment in which they can actively participate, should they wish to do so. However, as the patients at the Teppe have made clear, their life projects (be it working, friendships, or love relationships) are their private domain. However, that does not mean that they seek full autonomy in designing and making these projects. The healthcare team helps them to develop the capability to elaborate these choices, in relation to the limitations of their disease. Thus under the patient life empowerment model, the healthcare relationship will also be one in which the healthcare relationship is propitious to developing capabilities. For this to happen, it will need to be a relationship in which time and resource constraints do not take over this fundamental relationship. Let us now explore several concrete actions which will change in healthcare institutions with our patient life empowerment approach.

1. The treatment plan: We have discussed how healthcare outcomes from the biomedical perspective seek to work toward a healthcare plan which ensures adherence. The patient life empowerment approach has a different result in mind, one in which the patient will be capable of flourishing in terms of their life projects. The difference in the end goal of healthcare plans between patients and healthcare providers right now have catastrophic effects: in the previous chapter, we have seen how the medical model of treating epilepsy

[761] *Ibid.*, p. 11-13.

turned a 7-year-old boy into a zombie. The patient life empowerment approach, however, was one in which the boy could continue his development. It was also one which was acceptable to the healthcare provider, the family, and the patient himself because he could continue striving. Thus, we propose the end goal for the treatment plan in our approach to consist in: *prioritizing those treatment plans which are acceptable to the individual patient, notably because they allow them to continue to strive toward their life projects.* As the threshold to be healthy in patients' conceptions is tied to patients' overall ability to flourish in spite of the disease and/or medication, doctors can facilitate this capability by exploring with patients and their families an acceptable treatment plan based upon their individual needs.

2. Contributions of diverse healthcare providers to stimulate capabilities: as we have highlighted, doctors (and thereby healthcare institutions) can help patients toward development and use of their capabilities in the space of the consultation if they are able to offer a facilitating environment. However, that is not to say that we are putting all of the weight on the doctor's shoulders or that we are ignoring the vital roles of other healthcare professionals to help patients toward their capabilities. At this end of this chapter, we will be discussing a case study that mobilises diverse healthcare providers in stimulating patients' capabilities. Due to the realities of healthcare today, we in particular see a role for healthcare professionals, such as specialised nurses, who will be able to provide additional time for patients outside of the consultation to develop their capabilities. This is a model increasingly being provided in epilepsy patient care.[762]

***3. Epistemic Contributions of Patients and Families*:** the main ambition of this thesis was to seek the epistemic contribution of patients. We hope that we have achieved this goal by proposing the patient life empowerment approach. What this research shows, however, is how little healthcare programming currently reflects the patient's perspective. To move toward patient (or person) centered and patient empowering programming in the future, further epistemic contributions of patients will need to be solicited. This thesis has

[762] For the past several years, the Teppe has led the way in the definition and recognition of advanced practices of specialized epilepsy nurses. They have also invested in a nationwide hotline staffed by nurses to provide regular contact with patients needing extra assistance to the overall epilepsy community in France. For more information, please see: Omay, O., Petit, J., Luiggi, F., 2017. *La Teppe: The Epilepsy Center, Tain l'Hermitage, France.* Epilepsy & Behavior 76, p. S9.

proposed several methods to help solicit these contributions; others can be developed, or focused on other actors (such as families). In these discussions, we need to include not only those expert patients who can easily fit into biomedical models and "talk the talk" of doctors. The capabilities approach's strength was its demanding nature to ask us to include those who are the most marginalized and the most vulnerable.

In our borderline case study of refractory epilepsy patients, we sought the epistemic contributions of those patients who are regularly excluded from such discussions, and our patient contributions showed us just how illuminating these contributions can be. It is time to solicit diverse patient perspectives in healthcare decision-making and planning if we wish to truly move beyond paternalistic models. Given that the bedrock will continue to be in the patient-doctor relationship, we recommend policy focused on facilitating epistemic contributions within these relationships. For this to happen, a first step will be to give healthcare institutions the time and space to develop relationships with their patients.

Dealing with Fear

Another important aspect that we will need to take into account in the patient life empowerment approach is fear. We have already seen that our patients are "sick" given their inabilities to flourish in society due to fear, disgust and the resulting stigma and marginalization. Many patients are currently below the threshold of being healthy due to these factors. They are not able to thrive in their environments due to various manifestations of fear by others. In addition, fear is also linked from the patient's perspective to being healthy in terms of gaining control of their seizures. As we saw with Melanie, strong emotions — such as fear — even triggered her seizures. Thus fear and anxiety also stop patients from being healthy and from developing and using their *capability sets*. If we take seriously the social structures involved, this means reducing the fear and resulting stigma *felt* and *enacted* in society toward them. We can already start by reducing this fear in the healthcare provider relationship.

3.5.3. PLE vs Other Approaches

Having now proposed the patient life empowerment model, we will need to answer in what ways the PLE approach brings something new to the other proposals identified in Chapter 1 of this thesis. In this section, we will first of all examine the biomedical proposal, before looking at the Patient Activation Measure, and finally the empowerment caring model. We will not discuss the patient engagement or patient-partnership model as their difficulties for the approach we are seeking have already been highlighted.

The Biomedical Proposal

In our discussion of the biomedical claims to patient empowerment, we discovered a number of problems which were clarified by the patient life empowerment approach. The first is that patients will be empowered as they wish and desire to be so. We cannot assume that the patient will wish to share all intimate details with the healthcare practitioner, as the biopsychosocial model may lead us to believe; instead the focus is on the patient and their choice of whether or not to participate in the healthcare relationship and to what extent. This includes their choice of what information to share. Some information may not only be in the private domain of the patient, but it will also be their means of exercising control of the disease on their own terms (such as developing experiential knowledge to decrease their seizures). Secondly, we can more fully understand that if we want the doctor to make the space and time for patient participation into the healthcare plan, they need a facilitating social and economic environment. If healthcare institutions reduce this time, then we cannot expect patients to be able to exercise this capability nor for healthcare providers to support them. In addition, through the help of our patients, we have resolved how a life empowered patient can help the doctor by giving input into treatments and research for other patients. Thus the life empowered patient does help doctors in their practice.

Also we can now partially support Biomedical Claim 3, which allows patients and doctors to work together to create a personalized treatment plan (although here we will favor an *acceptable* treatment plan). However, we do not guard an unachievable ideal of a fully equal partnership, and we recognize that patient participation will vary depending on patient and their facilitating environment. In particular, we understand that the level of participation and co-decision making has a lot to do with how much the doctor allows for the patient's participation. In our approach, we put responsibility on the doctor (but also on others) in helping the patient toward their full capability of participation in this relationship and to move the goal toward an *acceptable* treatment plan for the patient.

The final assumption of the biomedical model of empowerment now needs reformulation. In our patient life empowerment approach, we see adherence as a possible component of patient empowerment, rather than the end goal. We now have a new end goal in mind: helping the patient toward a treatment plan which will facilitate (or at least not block) their capabilities to make their life choices. Adherence is a means to an end, but it cannot be the only end. We have seen how patients with severe diseases such as epilepsy saw the value of taking medication when it helped them to be healthy. Therefore let us work with patients to find a healthcare plan *acceptable* to them, in which they are able to continue to be active and to engage in their life projects. Adherence will likely, but not necessarily follow, but it is more likely to follow when the treatment plan allows them to continue flourishing.

As we can see, the patient life empowerment model helped resolve several difficulties of the biomedical model, especially by clarifying how patients help doctors, and what a personalized treatment plan means to the patient. However, we cannot accept the biomedical's focus on adherence (only) and propose that we instead see the end goal of the treatment plan as helping the patient be capable of pursuing their life projects.

The Patient Activation Measure

As discussed in Chapter 1, the Patient Activation Measure is first of all, a healthcare provider and healthcare institution developed measure, in which the patient is evaluated by the healthcare provider according to a pre-defined process of evaluation. Our model instead seeks the patient's understanding of empowerment. Our conceptions are not fully compatible, as they have different actors and priorities. However, can they be complementary? While PAM may help healthcare providers measure their ideas of patient empowerment, the problem with the patient activation measure for our purposes is that it seeks to develop capabilities as a means of encouraging certain functionings. The measure seeks, in CA's language, to decide the conceptions of good for our patients. For instance, in the PAM, functioning will include maintaining lifestyle changes and handling symptoms on their own. The PAM therefore seeks to "responsabilize" the patient to develop certain health related attitudes and behaviors.

As we have seen, this wording does not take into consideration the importance of the facilitating environment. It also does not engage the wider responsibility of others in helping patients toward this level of activation. Notably, the second step in PAM is to help patients develop the confidence and knowledge necessary to take action, but it does not

elaborate how doctors and healthcare institutions will create an environment in which patients can act. The CA approach and our patients helped us see how much we need others to make this happen. Thus the PAM, while being attractive for its dynamic approach to patient empowerment in a certain temporality, falls short from the patient's perspective as it does not take into consideration the role of others in ensuring patients can actually function (as the model tells them to do from a paternalistic point of view!). It is also too narrowly focused on the person as a patient, rather than as an individual in society, to take into consideration our patients' point of view of being healthy in their overall environments, and as agents working toward their life projects.

Empowerment Caring

As elaborated in Chapter 1, empowerment caring is an inspiring idea that helps us to understand that the doctor and patient's needs are mutually important. However, our patient life empowerment approach takes a stand, by focusing on the individual patient and what they were seeking from empowerment. That is not to say that doctor's needs should not be prioritized; on the contrary, without taking into account the social environment, we will never achieve patient life empowerment. However, the CA allowed us to prioritize the needs of the individual patient first and foremost. As discussed in the section on empowerment caring, there is little said about the (potential) tension between what the patient could want — in terms of their opportunities to be able to plan their lives — and what the doctor wants for the patient, which could amount to stopping seizures at all costs.

While the idea of empowerment caring allowed us to see that a good result might be one in which the doctor and the patient were able to make together, there will continue to be misunderstandings between the patient and the doctor, or between the worldview of doctors treating the disease, and the patient envisaging their lives. In addition, what empowerment caring is missing is this focus on the patient's desire to be able to plan and act on their life projects. For our project, we can reformulate the empowerment caring model from the patient's perspective, by proposing that if there is mutual empowerment caring to be done, it is the goal of working *with* the patient toward a treatment plan *acceptable* for the patient in terms of their *life projects*. The emphasis will be on the patient's life projects and their capacity as agents to work toward their life projects. The goal is now clear and allows us to imagine how the two parties can work together.

3.6. Family Life Empowerment

Having formulated the patient life empowerment approach, we will now formulate what a family life empowerment approach will look like. Our case study of epilepsy was a borderline case in terms of family relationships. In the first place, we can understand that family members (and/or friends that are close to the person with epilepsy[763]) have considerable means to help the PWE with their treatment and in monitoring their seizures. They are familiar with the disease through regular contact, but they also have a unique access to the experience of the seizure, which their family member often does not have. Given the memory problems associated with epilepsy, they are often those that can "remind" the family member of the manifestation of the seizure or help with medication timings and other factors related to their treatment. They are equally present in many cases in the consultation and are actively solicited by both the doctor and the patient during the consultation for their testimony. In this disease, we can talk seriously about a patient-family-doctor relationship to help the patient live better with their disease.

However, the role of the family extends beyond the consultation and into the private domain of the patient, notably by the facilitating role that they can play in helping their family member design and make their life projects. They are thus of particular concern in our patient life empowerment approach. While these persons can be of considerable support to their family member in these life projects, they can also become the means to prevent their family member from flourishing. As discussed in Chapter 2, because of the considerable risks posed by epilepsy, family members try to protect their loved one from danger. However, while starting from good intentions, in becoming overprotective or in projecting their own ideas of flourishing onto the person, family members sometimes become not "sympathetic others" but "destructive others." We have seen examples of this throughout Chapter 2: the mother who does not accept the disability

[763] We use the term "family life empowerment" here as there is no close translation of *proche* in English; by using the word family, we are not implying that only family members can be of support to patients. Family members are not necessarily familiar with their children, siblings, friends, etc. and not necessarily their natural carer. Friends and other forms of affiliation can be just as necessary (or more necessary) to the person's flourishing than a family member, depending on the family and on the individual. Our family life empowerment approach has a wider view of families to include those who are "familiar" with the patient, including siblings, children, extended family members, in-laws, etc. In other words, by using the term "family life empowerment" we are in no way suggesting an exclusive parent-child relationship, although in the case of epilepsy, it is often parents who do accompany their (adult) family members to consultations and continue to support their children throughout their lifetimes.

of her daughter; the son who does not let his family member leave the house because he is scared for her seizures; the 40-year old woman who was obliged to live in a medical-social center to be away from her mother who wanted her to stay at home.

As Nussbaum expresses it, "*family both fosters and undermines human capabilities…it thus has a very strong claim to be regarded as part of the basic structure of society, and among those institutions that basic principles of justice are designed to regulate more directly.*"[764] We argue, in agreement with Nussbaum, that as this overprotection and fear crosses into the medical domain, preventing an adequate treatment plan for the patient (as we saw in the elderly woman's story in China in Chapter 2), it is also concerned with our subject of patient empowerment and the way that institutions can support patients. In addition, as we have conceptualized the patient's view of empowerment as patient *life* empowerment, now we are also concerned with what is often considered the private domain of family life. We are concerned with how to help patients achieve patient life empowerment and therefore what goes on in the family comes into the scope of our approach.

Nussbaum's capability approach focuses on the kinds of social support that persons will need within social institutions – and other forms of affiliation such as families – to develop and support their capabilities.[765] Nussbaum does see an important role for the family in nurturing capabilities; however, the emphasis still remains on stimulating the individual person's agency. As she expresses it, "*the family as such has no moral standing with the core of the political conception. It is persons who have moral standing. We are interested in the family as a locus of person' development, association, expression, education, and so forth.*"[766] In our approach, we are therefore seeking an enabling role for the family (the kind of care they can provide for the person) to allow patients to flourish through this affiliation. We do however impose limits on this participation, by putting our focus on helping the individual patient become empowered. Our proposal for a family life empowerment approach is the following:

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[764] Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 270.
[765] Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. The Belknap Press of Harvard University Press, Cambridge, Massachusetts London, England. p. 220.
[766] Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 251.

Family life empowerment (FLE) approach: *A conceptual framework that seeks participation for family members in helping their family member (and/or friends) to flourish in line with their capabilities. Family members in the FLE approach may cooperate with the patient, healthcare provider, and others to support their family member to the level of participation as desired and needed by the patient.*

In the FLE approach, family members will receive assistance in order to overcome their fear of their family member's disease and enable them to find ways to support their family member in their life projects.

Supporting the patient does not mean, however, taking the place of the patient, either in their life choices or in their treatment plan.

In our FLE approach, we see an important participation for the family in supporting the family member develop (and sometimes implement) their capabilities, both inside and outside the consultation room.[767] We must insist however that while providing assistance through others does become an important part of our approach, our focus remains on helping support the individual patient's agency.[768] We use the terminology *for the patient* to signify that the focus here is on the patient, not on what the family member or on what the doctor wants or needs. The goal of the FLE approach is to provide an enabling environment for the patient with the support of the family. We are again not talking here of a person fully able to decide and to flourish on their own; instead we are including a considerable role for the family to help their family member to develop and use their *capability set*. To be clear, the emphasis in our approach is for the family to support patients in the elaboration of these capabilities, not to take their place (either in their life choices or in the treatment plan). However, we recognize that families in particular can play a facilitating role in helping patients to become empowered, if they are able to act

[767] As discussed in the previous chapter, we will not extend Winnicott's idea of "holding" here as some theorists have done when examining the role of social institutions. Our ambition is to give agency to patients to be able to flourish in their own ways with the help of the family. We are not convinced that the idea of "holding" gives enough agency to the patient as it places responsibility on society to achieve a holding environment. The CA approach, on the other hand, involves both individual and collective responsibility and seeks above all to give individual agency to the patient.

[768] Our approach is compatible with Tronto's approach to care, as we signal that "caring about" one's family member means on the one hand recognizing that care is necessary; while "caring for" means that we will assume some responsibility for the need and determining how to respond to it. However, we will use the wording of the capabilities as it signals the person's being cared *for* has full capacity for agency in all phases of caring. See also our commentary on patients helping others patients (being givers and receivers of care) in this chapter. For more information on Tronto's phases of care, see: Tronto, J.C., 1993. *Moral boundaries: a political argument for an ethic of care*. Routledge, New York. p. 105.

with and *toward* their family member without fear. The family's participation includes the healthcare plan and treatment, but it also involves a wider cadre: supporting their family member to develop, plan, and implement their life projects.

However, we must be careful to ensure that neither the family member's fear of the disease, the projected fear of not performing in society, or their intentions to care for the patient interferes with the patient's flourishing by taking the place of the patient. In our approach, learning about the disease for the family means learning about the disease and the treatment, but also accepting their family member's realistic limits because of their disease. Thus the role we are seeking is one in which the family is informed to the greatest possible extent of the disease, in order not to be afraid, and to know how to support the patient when they are in need of assistance, but not to take the place of the patient, either in the healthcare plan or in their overall life projects. Our aim in promoting *learning about the disease* is also to discourage unrealistic expectations of performance onto our patients. In their own way, family members must find a way to accept the disease and the limitations of the disease on their and their family member's life. To return to Nordenfelt, their capability to *adapt* to their family member's disease is also important.

3.6.1. Implications for Families and Institutions

Using this definition of family empowerment, let us investigate the practical solutions to recommend for healthcare institutions and/or patient associations to help overcome overprotection by family members. On the one hand, it remains difficult to impose an easy solution, as we are speaking of the private domain, even though as we have argued, this private domain crosses into the medical domain. As we saw Chapter 2 in the patient's fear, death is a very real possibility to the person who experiences seizures. We cannot blame the family member for wanting to protect the person with epilepsy from danger: it is not only a biological paternal/maternal/sibling instinct, but it is also one that can be an accurate evaluation of the risk at hand. However, we can suggest some practical implications for healthcare institutions and patient associations to both encourage an enabling role for families and to help them overcome overprotection.

In the first place, we recommend extending patient empowerment programs to families, so that they can learn better about the disease and be less scared. These programs can either be integrated in some temporalities with their family members, or be entirely separate programs specifically focused on family members' needs. However in both

instances, the focus will be on a family member *helping* the patient manage their disease in terms of treatment but and in outside activities. Rather than focusing exclusively on what restrictions PWE must obey to stay safe, we can also imagine modules which may help train family members in how to nurture capabilities in these patients, including trying new activities that patients may be scared to do because of their disease. Teaching family members how to help patients engage in reasonable risk will also help them see the full capability potential of their family members. Another important module can be on acceptance, as family members will need to accept in their own way the disease of their family member, although this will necessarily be a different learning period than for the patient. In turn, healthcare institutions can also provide counseling for family members to help them with the difficulties of caring for their family members.

All of these suggestions show possibilities to develop empowerment programs for families to move toward the family life empowerment model in institutions. In turn, patient associations can also bring together family members to discuss their difficulties of living with epilepsy, as well as informing them about the risks of overprotection and strategies to avoid it. Specific groups for families in patient associations can also help family members engage in reciprocity toward others in similar situations. Patient associations can also provide individual and group support for families, in particular by educating them on strategies to limit/overcome overprotection.

Now that we have argued for both the patient life empowerment and family life empowerment approaches, we are now ready to move into the final section of this thesis, which seeks to show how the PLE “improvement approach” may look like on the ground.

3.7. Reverse Engineering Approach to Patient Life Empowerment

In this final section, we will use a reverse engineering approach to understand how one institution provides a patient life empowerment approach. Using Otto and Wood's definition, we define reverse engineering as a process wherein a product is observed, dissembled, analyzed, predicted, and documented in order to understand and represent the instantiation of the product.[769] In other words, the goal of reverse engineering is to identify the relevant components of a product in order to produce something similar. Reverse engineering's potential lies in its ability to establish workings of systems and to understand how to reproduce results or to reconfigure them for new situations, environments, or needs. Thus one of the main issues in this approach concerns whether the resultant explanatory models given by reverse engineering approaches represent the relevant components permitting understanding of a phenomenon, and their ability to distinguish from irrelevant parts or an individual user's actions.[770]

For our project, what we mean by a reverse engineering approach is that we seek to unpack the relevant components which have made the patient life empowerment approach a reality for one healthcare institution in order to understand how to accomplish something similar or just as relevant in another healthcare environment. Thus what we are seeking in using a reverse engineering approach is an analysis allowing us to unpack the relevant components which allowed this institution to practice a patient life empowerment approach.

Having gone through the reverse engineering process, the next step in Otto and Wood's reverse engineering model includes the redesign of the product to fit the needs of the new structure and/or environment. However, we are not advocating a replication of the product, as some reverse engineering processes might do. We instead recognize that each institution and/or context will adapt such a structure to their own needs. Thus in reference to Otto and Wood's model, we propose to (only) participate in the first phase of the reverse

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[769] Otto, K.N., Wood, K.L., 1998. *Product Evolution: A Reverse Engineering and Redesign Methodology. Research in Engineering Design 10*, p. 226.

[770] One of the principal questions asked in reverse engineering is the *what if* question, in other words if the component or user were different, would this change the final result? For more information, see: van Eck, D., 2016. *On Testing Engineering Design Methods: Explanation, Reverse Engineering, and Constitutive Relevance*, in: *The Philosophy of Science and Engineering Design*. Springer International Publishing, Cham, p. 70-71.

engineering approach, which is the analysis of the phenomenon in order to establish the necessary parts. We will leave the redesign process to individual healthcare institutions.

This institution is (of course) the medical-social institution of the Teppe, which has been the focus of this chapter. We are proposing the Teppe's formulation of the patient life empowerment as an achievable ideal[771] because it already exists. The Teppe is both a French exception, due to the specificity of its healthcare plan, but also as part of a European network.[772] While in other regions of the world, epilepsy centers have disappeared, they still exist in western and northern Europe, providing a unique model of care for patients with severe epilepsy. These centers offer a unique form of outpatient and inpatient care and have become a European exception in calls to cut healthcare costs worldwide.[773]

In proposing this institution as an achievable ideal, we are not suggesting that this kind of institution is adapted for all patients. A live-in institution is not the solution (thankfully) for most patients with chronic diseases. If patients are at the Teppe today, however, they are there because of the complexity of their cases and their need to develop *capability sets* to be able to plan their lives. Such an institution allows patients to explore their life possibilities in a safe[774] environment, going to the limits of their possibilities of their life projects, without fear. Our example is therefore intended for inspiration, to understand what such a structure may be able to offer to other institutions.

The healthcare plan at the Teppe is very close to the ideal that Martha Nussbaum seeks for persons with disabilities in her capabilities approach. It seeks to develop the maximum capability opportunity for patients with significant social, medical, and

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[771] We call the Teppe an achievable ideal rather than a utopia. Epilepsy centers have disappeared in other places in the world following the general closure of asylums. It continues to be debated in France and across Europe whether or not the need for specialized centers can justify patients' full-time residence. Given these continuing debates, using the word utopia may cause controversy. For debate on continued relevance of these centers, see: Steinhoff, B.J., Chatrou, M., Hjalgrim, H., 2017. T*he European Association of Epilepsy Centers (EAEC): Just Old Europe or a modern model?* Epilepsy & Behavior 76, S1–S2.

[772] This network is called the European Association of Epilepsy Centers (EAEC). The founding members are in Germany, Denmark, the Netherlands, Germany, United Kingdom, Norway, France, and Switzerland. For more information, see: Steinhoff, B.J., Chatrou, M., Hjalgrim, H., 2017. *Introduction: The European Association of Epilepsy Centers (EAEC).* Epilepsy & Behavior 76, S3.

[773] *Ibid.*

[774] What we mean by "safe" is that the institution has personnel on staff who know how to react/treat the patient's epilepsy, as well as providing an adapted living and working environment which reduces the risks encountered during seizures.

psychological burdens, whether or not this is, as Nussbaum calls it, *socially useful*.[775] The Teppe has made the commitment to give significant resources to persons with disabilities to help them to flourish in their life projects. The healthcare plan implemented by the institution, as we will see, in turn facilitates patient-to-patient reciprocity, as it allows a space in which patients with significant disabilities become resources to other patients and doctors. If we take seriously Nussbaum's proposal to ensure each and every person has achieved a set of capabilities, then our patient life empowerment approach can use this achievable ideal to think about how to guarantee such commitments for a wider group of patients. In her approach, Nussbaum argued that securing justice for persons with significant disabilities remained the priority due to the sequelea of stigma and discrimination. If at the Teppe these types of entitlements have (already) been secured for these patients, is it not now time to extend them to the rest of the epilepsy patient population?

In order to identify the relevant components permitting understanding of the Teppe's patient life empowerment approach, we have relied on *both* healthcare providers and patient's perspectives on what they need to establish the patient life empowerment approach. For healthcare providers, this takes the form of what tools/environments/support networks they will need to work with patients and other healthcare providers; while for patients, this takes the form of discussions of how they are able to take advantage of the so-called personalized project at the Teppe to see and act upon their opportunities. In terms of what healthcare providers need to implement a patient life empowerment approach, we will focus in particular on the policies and infrastructure of the institution as a whole rather than their specific approach/innovations, in order to distinguish this from individual healthcare providers' actions/preferences/expertise they use in their professional work. This is in order to avoid the user factor which may lead us to individual specificities rather than policies/actions of the institution as a whole.

Through our analysis, we have identified eight necessary components to establish the patient life empowerment approach at the Teppe, which includes providing a facilitating environment for healthcare providers (in their work) and for patients (in their care). These components include:

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[775] Nussbaum, M.C., 2007. *Frontiers of justice: disability, nationality, species membership*, First Harvard University Press paperback edition. ed., The Tanner lectures on human values. The Belknap Press of Harvard University Press, Cambridge, Massachusetts London, England. p. 129.

Table 14: Components of the Patient Life Empowerment Approach

1. National legislation establishing the cadre to work actively with the patient
2. Integration of life projects into the healthcare plan
3. A clear responsibility for each actor (healthcare providers, patients)
4. Flexibility allowing for evolution in the healthcare plan
5. An absence of fear in the healthcare relationship
6. Epistemic contributions of patients forming a necessary part of the design, implementation, and evaluation of the healthcare plan
7. An interdisciplinary healthcare team to assist the patient in elaboration of capabilities
8. Spatial and architectural spaces of hospitality

Some of these components are necessary for healthcare providers to be able to provide a patient life empowerment approach for patients (1,2,3,7,8) while others were developed to allow patients' epistemic contributions (3,4,5,6) into the healthcare plan. What becomes clear from this list is that both healthcare professionals and patients need to be supported — and to have a supportive environment — in which to work toward the patient life empowerment approach. Thus providing a methodology to work with patients will fail when healthcare providers are not allowed the spatial proximity and architectural spaces of hospitality in which they do their work. Similarly, only focusing on healthcare providers' needs will not enable patients to contribute to their healthcare plans. While the end goal of the patient life empowerment approach is to provide a means for patients to develop their capabilities, and as we have made clear their needs are being prioritized, we recognize that the support network (notably healthcare providers, but also families) will also need attention; otherwise the environment becomes a blocking factor in the patient life empowerment approach.

Let us start our discussion with an illustration of the patient life empowerment approach as told directly from a social educator (to a nurse) at the Teppe,[776] to set the stage for our discussion before elaborating on the necessary components for the patient life empowerment approach we have identified above.

[776] This scene took place in the service of St. Joseph on the first day of focused ethnography at the Teppe in February 2019.

After a morning meeting, a replacement nurse is looking at the file of a patient, Henry. She was surprised that it was marked in the file that they were waiting for Henry's permission before sending the internship report to the workplace that had supervised him. She directs her question at a social educator,[777]

Nurse: *"This is going to seem crazy, but I don't understand why we necessarily need to ask the patient for permission to send this internship document."*

Social Educator: *"Yes, we do! It's important that the patient is engaged in his project, so we need his validation. In a not so distant past, we wouldn't need to ask the patient's permission, but now it's required. Since the 2002/2005 laws*[778] *and all of that, the patient has the right to ask, to question, etc. We are obligated to do so, it's just like that. It's their project, it belongs to them. Even if they have difficulties, it's our proper role as social educators to accompany them, and to explain the procedure."*

Nurse: *"I totally agree that patients have the right to know what is said about them, in all aspects of their care, but what I find strange is the procedure. If I go to see my primary care doctor, and she sends me to see the specialist, she is not going to ask my permission before sending my file to the specialist. It's understood when I said I was willing to see the specialist. I don't understand why we need to ask the patient if we have the right to send the evaluation."*

Social Educator: *"No. It's the formulation. When I say that they are engaged in their project, it means that we accompany them. We can't just call the place where they did their internship to ask how it went."*

Nurse*: "Ah! It's crazy how it's changed!"*

Social Educator: *"Of course! We have come into a dynamic where the patient is the center of his care. I think it's a good step. The patient is really engaged in his project. The first interlocutor is the patient. It wasn't us that had the internship. He's the one who participated; he's the person who was activated. We, as social educators, we have another vision. We are there to accompany them in their daily life, in their project."*

Nurse*: "I didn't see it like that."*

Social Educator: *"It's true that at the end of the day, of course, the evaluation is going to be sent. It would be impossible not to do so. But what is interesting, is if the patient refuses, is to ask him why. Are you scared? Are there things that you don't want inside, etc.? That's the social work that we put into place. It liberates speech and it makes the patient responsible for their project. There is participation in action, it's like that they are actors. And of course, on other points, they are actors. They have the right to refuse care as well. If the patient doesn't want a particular medicine, the doctor is*

[777] There is no "good" translation of the job of *educateur* in English. As it is different from that of a social worker, the word *social educator* has been favored in the text.

[778] Law number 2002-2, 2 January 2002 in reference to social and medico-social actions, n.d. and Law 11 February 2005, For equal rights and opportunities, participation and citizenship of people with disabilities.

going to counsel him, he's going to say, 'here are the benefits of the treatment, what it is going to do.' If the patient continues to refuse the treatment, he's going to propose something else. We are there to advise, it's a negotiation. However, if the patient doesn't adhere to the social educator's project, to the healthcare plan, we say, 'OK, you refuse our care, you refuse to work with the social educator, then you shouldn't be here. You have the right to say no, but you should go to another center.' All this doesn't surprise us, because we work with it everyday. For someone like you who doesn't work in a service with a social educator component, it can seem surprising."

Nurse*: "It didn't take my hair off, but it surprised me."*

Now we have an overview of the way that healthcare providers work with patients and between each other. We can also envisage how they see their role in helping patients. Let us now proceed with the necessary components that will enable the patient life empowerment approach. We can characterize these components within two subsections: an environment allowing for epistemic contributions by patients, and a working environment for professionals enabling them to work with patients and other professionals, allowing actors' epistemic contributions to emerge.

3.7.1. Legislation as a Cadre to Work Actively with Patients

Healthcare providers at the Teppe signaled a transformation in their means of working with patients with the introduction of new legislation in France, moving them toward the patient life empowerment approach. As Nussbaum has advocated, inputting capabilities into national legislation is a means of ensuring the stability of such priorities in practice, but also in the hearts and minds of the people for whom such legislation was developed. In the case of the patient life empowerment approach, the 2002 and 2005 legislation developed for medical social centers in France has served an overall architectural function by establishing the cadre to work actively with the patient. At the Teppe, these changes were at first met with resistance by some healthcare providers; however, they are now largely accepted and advocated for by professionals (they have entered the hearts and minds), as they have given a concrete way of working with the patient. The first is the 2002 legislation, which we will now discuss.

2002 Legislation

The first legislation, passed on January 2nd, 2002, changed the regulation of the medical-social sector in France by giving a new means of ensuring patient participation. Article L311-3[779] notably includes two components to move toward a patient life empowerment approach. These two components are 1) a healthcare plan focused on favoring the development of autonomy and reinsertion; and 2) the participation of the patient into the conception and implementation of the project of welcome and accompaniment.

The project of welcome and accompaniment (*le projet d'accueil et d'accompagnement*) has been translated onto the ground into what is called the *personalized project* (projet personalisé).[780] The term "personalized" specifically means three things: 1) that the patient is the focus of the healthcare plan; 2) that the healthcare plan is developed with the patient; and 3) that the healthcare plan is "personalized" with the contributions of different healthcare providers and the patient. The epistemic contribution of diverse healthcare providers is specifically sought because of the first clause of the law, which seeks to nurture patients' capabilities for "autonomy and reinsertion," meaning that the healthcare plan includes (not only) medical needs but also social needs fulfilled by an interdisciplinary team (doctors, psychologists, social educators, etc.).[781] What is also meant by "personalized" in this formulation is that that the project is developed with the patient, i.e. the project will be personalized in that it will focus on each person's individual needs for autonomy and insertion.

The law seeks to provide a legal cadre for patient participation, but without an obligation for participation for those who do not desire (or who are not capable) of participation;[782] and it gives concrete roles for healthcare professionals to support the patient in their personalized project. The law therefore provides the cadre for epistemic contributions from both patients *and* healthcare providers in the personalized project. In

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[779] Law number 2002-2, 2 January 2002 in reference to social and medico-social actions

[780] ANESEM, 2018. *Recommandations de bonnes pratiques professionnelles: Les attentes de la personne et le projet personnalisé.* p. 10.

[781] *Ibid.*, p. 11.

[782] The 2002 law gives rights not obligations for patient's participation in their personalized project. While professionals can encourage the participation, this does not in return mean that patients are obligated to participate.

terms of epistemic contributions coming from patients, the personalized project is recommended to consist of several stages of accompaniment and elaboration[783]:

> 1. First contact: establishing the requests of the person and forming an alliance between healthcare providers and the person.
>
> 2. Analysis of the situation: working with the person to identify social and professional competences to order to establish a realistic personalized project. In this stage, the family's analysis of the situation may also be included.
>
> 3. Co-construction of the personalized project: this stage involves integration of important life factors for the person into the personalized project, such as the lifestyle of the person, "first tries" and other methodologies to allow new and realistic ideas to emerge in a co-construction between the patient and the healthcare provider. It also seeks to clarify the institution's realistic capabilities to help build patients' wishes into the personalized project.
>
> 4. Deciding and fixing the objectives and activities related to the personalized project: this stage involves both authorizing and limiting the number of possible actions in the personalized project. Any decisions which impact the life of the person seek the person's participation as much as possible.
>
> 5. Planning, monitoring, and adjustments to respond to evolution: planning, monitoring, and adjustments to the personalized project in coordination with the person. Both persons and healthcare providers co-evaluate projects and make the necessary adjustments to the personalized project.

From this analysis, we can see that the patient is solicited to participate in every stage of the personalized project, from its conception, to its monitoring, and its realization. While the patient is not obliged to participate in the process, every means is given for the patient to participate. This is not to say that the person has the full control of the personalized project, but rather that each step is elaborated in affiliation, in which both the person concerned and the healthcare providers make concessions and come to compromises for what is feasible from both the perspective of the healthcare institution and that of the patient.

[783] ANESEM, 2018. *Recommandations de bonnes pratiques professionnelles: Les attentes de la personne et le projet personnalisé.* p. 20-32.

2005 Legislation

The second important legislation impacting the running of the Teppe was the February 2005 legislation, "For equality of rights and opportunities, participation and citizenship for persons with disabilities."[784] This law looks to generalize acceptability of disability in all domains of social life (education, employment[785], or transport) as well guaranteeing disabled persons the choice in their *life* projects (notably by provision for compensation and revenue in order to facilitate an autonomous lifestyle).[786] The legislation also seeks to remedy several areas of the patient life empowerment approach we have been seeking, notably by encouraging employers to hire disabled persons. In the case of the Teppe, the legislation has helped the center establish several partnerships with local and regional companies that hire epilepsy patients via outsourcing or in protected workplaces.

These are the two state level laws which have guaranteed the epistemic contributions of patients into the healthcare plan, as well as a focus of the healthcare plan on the patient's life projects. Now that we have investigated the legislative cadre, let us understand how the Teppe has used these tools to create a specific healthcare plan for patients with severe epilepsy.

3.7.2. Integrating Life Projects into the Healthcare Plan

The Teppe has used these two pieces of legislation to formulate their specific healthcare plan for severe refractory epilepsy patients. The personalized project at the Teppe has two goals: (1) to develop a life plan for the patient to see what the person is capable of doing (orientated toward work) and (2) a healthcare plan that seeks to stabilize the patient's epilepsy to the best extent possible. On the ground, it is difficult if not impossible to see which of these two goals is more important than the other, both for patients and for healthcare providers: indeed for one to succeed, often the other one must, too. Patients who are able to stabilize their epilepsy can sometimes proceed quickly with

[784] Law 11 February 2005, For equal rights and opportunities, participation and citizenship of people with disabilities.
[785] The law notably obliges employers with more than 20 employees to engage at least 6% of their staff among persons with disabilities.
[786] In 2016 this law was modified to contribute to accessibility for disabled persons in the Internet as well as alignment of rights according to the private sector. However, employers can accomplish their obligations in diverse ways: direct employment, outsourcing or service provision in a protected workplace.

their personalized project; while those who fail in their life projects such as work may have problems with their epilepsy treatment plan, as well.

As recommended by ANESEM[787], the patient is involved in all stages of the formulation and evaluation of the personalized project at the Teppe, to a greater or lesser extent based upon capabilities for participation, as well as their desires for participation. Throughout the process of the personalized project, the healthcare team and the patient regularly met to assess the progress of the project and to evaluate how the patient is moving forward with it. While the level of involvement by the patient depends on a certain capability of elaboration, and the process itself is controlled by the healthcare team via the patient file, the patient forms an important part of the process and is consulted before decisions are made.

3.7.3. A Clear Responsibility for Each Actor

The personalized project gives a clear role for each actor. Because of the personalized project, each healthcare professional has a specific role in the personalized project. They know their role and their possibilities to act *with* and *for* the patient (avoiding the "collusion of anonymity"[788]). For instance, social educators are the main professionals tasked with the *life objectives* part of the personalized project, whereas nurses and doctors take the responsibility for supporting the patient toward the *medical objectives* in the personalized project, and psychologists and psychiatrists help patients toward *psychosocial objectives* such working on their fear of their epilepsy and to work toward a less protective relationship with their parents. These objectives all have specific indicators within the personalized project.

This has permitted professionals to "be in their professional roles," giving them the space for "well-argumented choices" among each other based upon their separate areas of expertise. According to one professional, it gives the person a professional capacity, the capability to say, *"me, from where I am, I can act."* Everyone knows who is responsible for what part of the personalized project, and in turn the patient knows with whom to discuss what part of their personalization project. In return the patient's responsibility is also clear. This fits with the idea of collective responsibility as advocated for by Jean

[787] ANESEM, 2018. *Recommandations de bonnes pratiques professionnelles: Les attentes de la personne et le projet personnalisé.*
[788] Balint, Michael, and J. P Valabrega. 1988. *Le médecin, son malade et la maladie*. Paris: Payot. p. 80

Oury,[789] giving clear responsibilities for healthcare providers and for the patient.[790] The patient will decide her life objectives and to try her best to implement them. Sometimes this step is active (expressing her desires for a certain type of work), while at other times it is less active (such as reading the internship report). This means that patients are at the center of the healthcare plan, but they are not always actors in the healthcare plan organized for them. Therefore there are professional boundaries and roles which do not involve the patient, even if the patient is at the center of the healthcare work.

However both professionals and patients work toward a common goal: the success of the personalized project. Because the personalized project is a compromise between the requests of the patient and the capacities for support by the institution, the personalized project has been agreed, discussed, and negotiated before being put into place. Each actor knows the possibilities but also the limitations of the support provided. Importantly, each party has agreed to it before commencing the project. If patients take on and try their best to achieve the objectives in the personalized project, they need support and guidance to move forward with their objectives. The responsibilities for both healthcare providers and for the patient are clearly elaborated in the personalized project.

In terms of the healthcare plan, the head of the personalized project is also head of the service, who is usually the doctor of the service (and usually the neurologist treating the patient). This enables the healthcare provider to have a global view of the patient in terms of their life objectives because they have collaborated with the patient in the design and implementation of the personalized project. In turn, when doctors treat their patients for epilepsy, they have all of these life objectives before them to take into consideration in the healthcare plan. As the personalized project is always in the background and the end result of the healthcare plan, medications and other medical solutions are adjusted (when possible) to allow the patient to go toward these life objectives (toward an acceptable treatment plan for the patient in terms of their life projects).

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[789] Oury, J., 2007. *Psychanalyse, psychiatrie et psychothérapie institutionnelles.* VST - Vie sociale et traitements 95, p. 118.

[790] Patients at the Teppe also have collective responsibilities in terms of cleaning up after meals and/or helping formulate policies at the institutions, such as being a patient advocate (this is only a possibility at the institution's medical homes), similar to the ideas of collective responsibility advocated by Oury. For Oury's ideas of the hospital "Club" and how to engage collective responsibility in institutions, see: Oury, J., 2009. *Séminaire de La Borde du 25 octobre 2008.* La clinique lacanienne 15, p. 14.

3.7.4. Breathing Space: Flexibility for Evolution

The personalized project is not a perfect or failure-free methodology for working with the patient toward their life empowerment. Behind the development of the personalized project lie social factors such as *adapted preferences* which may have prevented the patient from expressing their desires or needs at the time of the development of the project.[791] Thus the personalized project allows for evolution in content. For example, by developing a capability of elaboration in patients during the personalized project, it may come to light that the patient did not really want to work in a wood workshop, and has a secret passion to be a florist; or that the person dreamed of working with wood, but in time saw that this was too dangerous given her seizures. The capabilities approach has allowed us to see that overcoming the sequelea of stigma and discrimination leading to adapted preference takes considerable time and assistance of others; here the Teppe shows us the means of overcoming adapted preferences which may not accurately express patient's desires through flexibility in evolution of the healthcare plan.

The temporality of the personalized project at the Teppe allows for adaptation and evolution. It follows the rhythm of the person: while a patient may be able to make rapid process in one area, other objectives may take more time. The importance of the personalized project is that it *takes the time it takes* for the individual person, rather than focusing it on the healthcare institution's temporality. This allows the treatment plan to adapt, or in other words, to be personalized, to the needs and rhythm of the individual person and their personal evolution in the project.[792] It therefore gives the breathing space to allow patients to be or to become empowered in the ways and means appropriate to them and in the temporality appropriate to them as individuals. Here we are working in the temporalities of the patient's needs, rather than the temporalities of the healthcare institution, the family, or the expectations of society.

[791] ANESEM, 2018. *Recommandations de bonnes pratiques professionnelles: Les attentes de la personne et le projet personnalisé.* p. 17
[792] *Ibid.*, p. 17

3.7.5. Interdisciplinary Healthcare Team

The personalized project is only possible because of a diverse range of professionals operating in coordination at the Teppe to help patients toward their life objectives: between nurses, neurologists, generalists, psychologists, psychiatrists, social educators, and other professionals, the healthcare team practices a global approach to care, taking into consideration the medical, psychological, and social needs of patients. The interdisciplinary team in each service is able to work together for two reasons: 1) the healthcare plan is centered around a common goal, the personalized project; 2) the spatial proximity of healthcare providers allows them to work together toward this goal.

A facilitating factor is spatial proximity: for instance, in the service of St. Joseph, both nurses and social educators share a common working room (and desk!) in the service. This allows diverse professionals to learn about their patients from other healthcare providers' perspectives based upon the work they are doing with the patient. A common document, the patient file, allows the staff to know what happened with a patient in the service since the last time they were working. Not only does the social educator know how many seizures the patient had last night, but the nurse knows how Henry's internship went. The interdisciplinary team and spatial proximity allow this information to be shared.

In turn, healthcare providers can learn from each other due to this spatial proximity and common approach through the personalized project. We have already seen an example of this from the social educator's side, when he explained to the replacement nurse how the personalized project worked. Professionals at the Teppe speak of learning (from a theoretical basis, via their training), but also from the ground. This method is not only "rich" but it also "softens" their professional boundaries, allowing healthcare providers to integrate new perspectives, for example the social educator perspective into the nursing professional's perspective, in order to have a global view of patients, and to help them to work toward their life projects, by taking into consideration all the factors influencing the person.

3.7.6. Epistemic Contributions of Patients

The epistemic contributions of patients to their personalized project are the most important part of the process at the Teppe. Healthcare providers signaled that patients who were not able to participate in the design and elaboration of their personalized projects often saw the personalized projects fail. The involvement of the patient into the personalized project is not only a "marketing scheme," or a "recommendation" by the health authorities; it is actively solicited by healthcare providers at the Teppe in order for it to have a chance of being successful. Unlike the treatment plan, which is decided (mostly) by the doctor, but with input from the patient, in order for the patient to work on and accept her personalized project, the patient needs to be the main actor, because she is envisaging her life. In other words, her epistemic contribution is not only *valuable*, it is *necessary* to ensure that the objectives developed in the healthcare plan reflect the patient's priorities.

Even if the healthcare providers at the Teppe control the final process (such as narrated by the healthcare team that the internship evaluation would still be sent), the most important part of the process remains the patient's contribution. However that is not to say that the patient will be encouraged to be fully independent in this decision making process or that they may make unreasonable requests; with the personalized project, healthcare providers can assist the patient toward a process in *adaptation*. In other words, in order to solicit and help develop the contributions of patients, healthcare providers are vital contributors in helping patients develop realistic life choices.

3.7.7. Developing Capabilities of Elaboration in Patients

Because patient involvement and collaboration is so important for success of a personalized project, the healthcare team accompanies patients toward development of their capability of practical reason. Healthcare providers invest time into developing the patient's practical reason through two methods: 1) helping patients toward elaboration of choices and desires and 2) helping them critically evaluate past failures in order to move forward toward new objectives. This is broadly in keeping with a patient-centered approach focusing on cultivating a patient's capabilities to make their life choices.[793]

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[793] Entwistle proposes that treating patients as persons in the patient-centered care model be defined as, *"recognizing and cultivating their person-al capabilities"* through actions such as cultivating the individual's capabilities for autonomy. This includes encouraging interpersonal relationships and professional support that

The first step to arrive at this capability is to develop patients' capabilities to elaborate their choices and desires. The lack of elaboration was identified by healthcare professionals at the Teppe as a blockage in their ability both to work with patients and for patients to succeed in planning their life projects. In return, while the capability of elaboration was not cited directly by patients during the interviews, patients spoke at length during the interviews about the importance of the healthcare team (particularly social educators) in helping them to both formulate and advance in their personal projects. In so doing, they described a process of developing a capability of elaboration with the help of the healthcare team. Healthcare professionals said that it was essential that the patient could elaborate choices in order to become active in the healthcare plan (and in their lives) as much as possible for three reasons:

1) To allow patients to develop their capability of practical reason (in order to make argumented choices about their life projects and/or healthcare plan)

2) To allow the necessary conditions for the success of the personalized project

3) To reassure the healthcare team that the decision came from the patient and not from the healthcare provider

The capability to elaborate choices was a point of departure to allow professionals to work with patients. One reason that elaboration was particularly difficult for patients at the Teppe was due to overprotection. Many patients coming to the Teppe have let the family take decisions in their place, leading to an in-capability to engage in critical reflection about their lives. Thus a particularity of the Teppe was to encourage development of this capability of elaboration. This included helping them elaborate what they wanted to do in their lives, suggesting various alternatives and possibilities, and letting them try out these capabilities in the various workshops or activities proposed at the Teppe.

Even in this enabling environment, this capability for elaboration was not easy for many patients at the Teppe, due to cognitive impairments, psychological problems, and other reasons. The need for healthcare professionals to "push" the patient toward making

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people may need to help check, develop, but also refine their projects. These steps toward practical reason identified here are a means of helping patients develop greater capacity for autonomy (with necessary adaptation), to the extent needed and desired by the patient herself. See: Entwistle, V.A., Watt, I.S., 2013. *Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centered Care.* The American Journal of Bioethics 13, p. 35-36.

"reasoned choices" was often necessary. As expressed by a healthcare professional, *"there are times, we as a team, we are actors for them, because we guide them, also because they need to be guided."* However one solution proposed by healthcare providers for these borderline cases was to propose to the patient a certain number of choices. In this way, although patients did not exercise fully autonomous decision-making, anxiety for decision-making was reduced (they only had to choose among several options), and at the same time the healthcare team could propose feasible, realistic options for the patients to take. Several patients even stated that this method helped them toward "argumented choices." This accompaniment, or to use the words of a patient, "to climb the stairs" was necessary to help certain patients progress in their capability of practical reason. As we have seen, the capability of elaboration was requested by healthcare providers to allow them to accept the patient's contributions in the healthcare plan; here we see how healthcare providers can help move patients toward this capability.

Nussbaum's capability approach helps us to understand how to work with these types of cases. She suggests that some opportunities may have to be done through a surrogate, if necessary, but in most cases, as we saw with Melanie, the key to developing this capability was accompaniment. Further, despite whether or not some patients may make it over the threshold, the goal remained the same: to encourage patients toward their maximum potential of participation and decision-making.

Steps toward Practical Reason: The Importance of Failure

Awareness of capabilities and in-capabilities gained through failure was also an important means to help patients develop their capability of practical reason. All of the patients interviewed at the Teppe had lived through multiple failures: in education, in professional or family life, because of their epilepsy, psychological, or behavioral problems. Indeed if they were at the Teppe — in an institution — it was because they had to a certain extent "failed" to find a way to live in society. The healthcare team at the Teppe said that some patients' fears of failure owing to past experience was so severe that upon arrival, there was often considerable work to be done with patients to "get them out of their fear" and to once again take risks to envisage what was possible in their lives. Part of the means to do so was through critical reflection on their past failures — to understand why their educational, work, or love relationships had failed — in order to be capable of planning their lives.

The role of failure here shows us the importance of others in supporting these capabilities. Reformulating ambitions in their life projects, owing to new circumstances (such as the diagnosis of epilepsy) was difficult for patients to develop alone; they needed a supportive environment to enable them to critically reflect on their failures and to develop both knowledge and the confidence to act on this knowledge. If failures made them think they were incapable of working, for example, the healthcare team could encourage them to try again and find a new type of workplace in which they could succeed. As we saw at the beginning of the chapter, Melanie went through this process and came out with a feasible work plan in a new field; for Christophe, since a full-time workplace was not possible due to his epilepsy, he was able to integrate an adapted workshop at the Teppe. The process of adaptation to these failures allowed these patients to envisage their life — and future — in society in a realistic perspective of what they were actually able *to be* and *to do*. This idea is in keeping with Nordenfelt's idea of health in terms of adaptability, of being able to adapt plans for one's life in terms of the realities of the limits of their diseases. This is not necessarily tragic: Melanie and Christophe showed us that they were capable of flourishing thanks to this accompaniment.

3.7.8. Absence of Fear

Our patients identified the Teppe as a "safe place," "the solution" "an escape route" and "a place where they felt free." By this, patients said did not feel scared either for themselves or toward others when they were at the Teppe. Those patients who could form friendships at the Teppe were able to live in relationships in their social worlds, as they were able to help others and to be helped by others. In return, healthcare providers at the Teppe were given the space to develop relationships with their patients, in turn reducing their fear in the consultation. We can see that healthcare institutions — but also wider society — can help patients to reduce their fear. Even more extraordinary for a condition such as epilepsy, this ability to live *with* and *toward* others, also seems to have an impact on their seizures. From these elements, we can see that a number of the problems of fear that we have so painfully described in the last chapter has been resolved at the Teppe. If we can imagine an ideal society for the patient with epilepsy, by which we mean one in which she does not have to live in fear, we would propose that everyone learns about epilepsy, in order to provide this kind of "safe space."

The reasons for reducing or eliminating fear, as we will see, were tied to patients' capability to gain a certain amount of control in their environment. Patients related that they did not feel scared at the Teppe for the following reasons:

1) The actors of the Teppe— patients and healthcare providers — reduced the patient's fear of the body by providing a safe environment

2) Fellow patients reduced their patient's fear by inviting them to engage socially

3) Healthcare providers reduced their patient's fear by admitting uncertainty in their treatment plans and taking the time to get to know their patient as well as supporting them toward their life projects

4) Separation from overprotective family members allowed patients to release the weight of others' fears

Other patients and healthcare providers reduced the patient's fear of their body: patients were able to decrease their fear around what would happen when they lost control of their body during a seizure at the Teppe thanks to fellow patients and healthcare providers. As almost everyone (healthcare providers and patients) knew how to deal with seizures, including basic first aid, or how to prevent risks that may happen during a seizure, patients were in turn less scared of having a seizure at the Teppe (and sometimes had less seizures!). As we saw with Christophe's story at the beginning of this chapter, both patients and healthcare providers had the knowledge and means to make sure that Christophe was safe when he had a seizure. In turn, this liberated other fears: patients tried sports, new hobbies, and new workshops because they knew that if they had a seizure during these activities, they would be "safe." This in turn helped patients release their own fears and envisage their lives.

Fellow patients reduced the patient's fear and helped them live *toward* others: we have described how often epilepsy isolates. As Christophe showed us, at one point he felt everything was "in chaos" and only wanted to stay at home. At the Teppe, patients described an important means of reducing fears through stimulating (but also conflictual) relationships with fellow patients. Nussbaum helped us see how important it was for our patients to live *with* and *toward* others in their environments. In turn, we saw that some patients conceived of empowerment as a means to help fellow patients, not only themselves. When arriving at the Teppe, often for the first time, patients met "epileptics like them," a place where epilepsy was even the norm. For once, epilepsy was not "that

bizarre disease" but a factor facilitating their social integration. One patient for instance described her integration at the Teppe as:

> *Mariam: "When I arrived here, I was very very shy, I had a hard time integrating myself with the others, and finally it was the other patients who said to me, but come with us, come! Don't be scared! And now my epilepsy is stabilized because I have less seizures. When I came here, I had at least ten per month!"*
>
> *Researcher: "Is it because you're feeling better that you have fewer seizures now?"*
>
> *Mariam: Yes, but I think it's also the fact to find my friends."*

This patient insisted that a factor in her stabilization was her capability of being *with* and *toward* others, in rewarding social relationships. As Barrier has proposed, the collective sharing of experience between patients allows the person entry into a new world in which there are others like them, making it easier to confront the non-sick and to feel and show oneself different in wider communities.[794] We are not suggesting that living in an institution does not come with conflicts and difficulties between fellow patients; those who described difficulties with accepting to live at the Teppe often were those who did not find friends in the service; however, when it is possible to integrate socially, this sometimes also had an impact on the reduction of their seizures.

Doctors reduced the patient's fear: fear was notably absent in healthcare relationships at the Teppe. Even when patients described a conflictual healthcare relationship at the Teppe, the word used was not fear. We can hypothesize that the absence of fear was due to several factors, based upon both healthcare providers' and patients' descriptions of their relationship: 1) proximity to the patient onsite allowed a relationship to form between doctor and patient; 2) the long-term aspect of the care plan (in most cases patients can stay at the center for up to four years) allowed the temporality necessary for this relationship to develop[795]; 3) the complexity of the epilepsy treatment allowed a more communicative relationship to emerge.

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[794] Barrier, P., 2014. *Le patient autonome*. Puf, Paris. p. 35.

[795] Like Balint's idea of the mutual investment company for generalists, who can develop a long-term relationship with patients through the long-term nature of their relationship, the special nature of the long-term relationship at the Teppe allows such a relationship to form and to be maintained.

Thus we can identify several elements here to reduce the fear toward patient and doctor, in particular the space and the temporality to establish a relationship and the admission of uncertainty by the healthcare provider. As we saw with Melanie, her long healthcare trajectory made her knowledgeable about her medication. She was aware that most medications were a trial and error process; in turn, her neurologist admitted the uncertainty of the treatment plan and admitted this uncertainty to the patient. Returning to her description from Chapter 1, while she does describe the process of finding the right treatment as being a "guinea pig," rather than causing frictions in the doctor-patient relationship, it instead created a space for trust between her and her doctor. She therefore describes an excellent relationship with her doctor, as he both "does not judge her" but he also listens to her needs and gives her a say in decisions about the treatment plan. This did not take away the suffering of being a guinea pig, but it did allow her to participate in the healthcare plan and for the doctor to be her *sympathetic other*.

Overprotection reduced or eliminated: the Teppe works actively with young people to help them see what they may be capable of doing; an important element in this, when arriving at the healthcare establishment, is to provide a "break" from their parents in order to move toward an active path. One patient describes the process as the following:

> Marie: *"So the Teppe, it was my escape route. The doctor X, that was my neurologist…for 30 years. He said to me…since you don't stop having seizures, it's better that they* (the Teppe) *take care of you and you can't manage alone…you are too scared of your mother. I had the jitters before speaking to my mother, the jitters of my life, because it was difficult to speak about such things because we are very close, and it was especially my mother who didn't want to let me go…I spoke first to my brothers, and they said to me, that it would be a very good solution. Afterward I spoke to my father and finally my mother, but she said, "no no, my child! Out of the question that you leave the house!" You see, it was not even worth discussing for her. So when I came here, she finally accepted it, but when I came here, the doctor said it was on condition that you don't see your mother for four months. And I said that it's not a problem if I don't see her for some time, it's not a problem if it's necessary.*
>
> Researcher: *Did you manage?*
>
> Marie: *Of course! well for me it wasn't difficult…for me it was basically a medication to do that…no, but it's true! Because to always wait at the house and to stay seated and to pay attention! Because at my parents' house I was not in security, I didn't feel safe…I could easily hurt myself. It was costly for me, to make them worry about me…so finally it was a solution…it was THE solution to the problem."*

As we can see from this patient's narrative, the weight of her mother's fear was costly to this patient, to her capabilities, but also to their relationship. This break from her family members' fear was necessary for this patient to release the burden of fear in this relationship, both for the mother and for her daughter.

3.7.9. Spaces and Architectures of Hospitality

A final component of the patient life empowerment approach at the Teppe that we will discuss is the spatial and architectural spaces of hospitality for both patients and healthcare providers. The design of space in an institution such as a hospital favors a culture, complementary or in resistance to the technical culture, which can change the experience lived by the user for which the project is designed.[796] With space and architecture, *care* can become more than just a *cure*, if it permits persons to take care of themselves and others in a hospital environment.[797] The Teppe has evolved into such a space both due to its unique history, permitting spaces and architectures of hospitality, as well as its unique care plan for patients, through personalized projects. It is not just a medical-social center for severe epilepsies; it is also one which welcomes its patients, residents, and healthcare workers in a space to live, to work, and to appropriate for themselves.[798] The hospital is always under construction, and it vibrates with activity all year long as new workshops, new art, and new activities for patients take place.

Architectural Hospitality

In the first place, the reason the Teppe exists at all is its geography, and especially its entanglement with its nearby vineyards. It is located at the outer limits of Tain-l'Hermitage, a town known for its chocolates, wine, and fruits. The Teppe has a long history: a noble family, the Counts of Larnage, established the Teppe in 1856 to promote their special anti-epileptic remedy, handed down from generations, which was made with

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[796] Pellerin, D., Coirié, M., 2017. *Design et hospitalité : quand le lieu donne leur valeur aux soins de santé.* Sciences du Design 6, p. 41

[797] Pierron warns that not paying attention to spatial attention means reducing architecture to its instrumental dimension. See: Pierron, JP. *« Pour une philosophie de l'attention spatiale. Architecture des soins et soin de l'architecture.»* In: Barrère, C., 2019. *Cahiers thématiques: architecture et paysage, conception, territoire, histoire, matérialité.* p. 137.

[798] *Ibid.*, p. 145.

bedstraw and soaked in the white wine from the hills of Tain.[799] The remedy was popular, attracting 200–800 people in May and September each year from all over France, when the Counts distributed it in accordance with the moon cycles. By the end of the 18th century, its reputation among the sick was enough to keep the establishment going, and even to flourish. In 1857, the Asylum of Epileptics came under the management of the Filles de La Charité (Girls of Charity) of Saint-Vincent-de-Paul, and remained so until the establishment was transferred to state control in 1975.[800]

While today a medical-social center, the establishment continues to mark its unique past: the bar for patients to socialize in the evening is named after that first remedy; an arch left over from its religious past still welcomes visitors to the site; and the chapel still remains a meeting place of the establishment. Today it is situated two kilometers from the city center of Tain-l'Hermitage, on a site of 32 hectares, which can be entered directly from the Rhone River. The city of Tain has "come to" the Teppe and it is now surrounded by its fruit and chocolate factories[801], although it still remains at its city limits.[802] It resembles a park with large green spaces dotted by bridges, animal enclosures and agricultural workshops, and with the art works of patients displayed around the site. All of these factors help patients to live long-term within the constraints of the institution; while for healthcare providers, it remains a world away from city hospitals.

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[799] For the full history of the Teppe, see Faure, Olivier. 1986. « *L'épilepsie entre malheur et maladie. Quelques exemples régionaux au XIXe siècle.* » Le Monde alpin et rhodanien. Revue régionale d'ethnologie 14 (2): 83–96 and Le Jeune, Karine. 2016. *Epilepsie, neurologie et psychiatrie en dialogue: une histoire en mouvement à La Teppe*. Paris; Editions Autrement ; La Teppe, l'humain en tête.

[800] Law n° 75-535 du 30 juin 1975 relative aux institutions sociales et médico-sociales., n.d.

[801] The smell of Valrhona chocolate factory can be smelled from one end of the Teppe, leading to suppositions on the weather by citizens of Tain and patients at the Teppe (i.e. if we smell chocolate, it may rain). While for some patients, this smell is inviting, others find it undesirable (inhospitable).

[802] Patients complained that the hospital was far from the city center (although there are now buses and it is possible to walk to the city center in about 30 minutes). This distance however continues makes it difficult for them to go to the city center for short periods. The establishment is currently experimenting new ways and means of integrating the establishment into the city; one of the ways is that it is "open" to outside visitors (i.e., people now cycle through the establishment on their way to work, etc.); there is a race that takes place each year for runners; patients work in protected workplaces outside of the establishment, etc. The compromise made by having a structure at the city limits does mean that patients have a safe environment in which they can act, without fear, as we have explained. It also remains difficult to imagine such a global approach to care without the large physical space that the Teppe has been able to provide due to its unique history.

Spatial Hospitality

The Teppe is today at the border of a hospital and a residence. We have already discussed how the spatial proximity to their doctors (and the possibility of seeing their doctors regularly) helped reduce fear in the doctor-patient relationship at the Teppe. In the hospital services, where there is the capability to accompany patients in their daily lives, patients view healthcare providers, and healthcare providers view patients, not only as patients or nurses, but also as "Melanie" or "Christophe." The personnel and the patients speak in familiar terms (*se tutoient*) between each other and relationships between patients cause intrigues among the personnel. They eat with the patients, observing them and being observed, and speak with them as much about their medication as the latest football match. The personnel of St Joseph wear a white coat only when there is a healthcare act required[803] and the patients are not, for most of the time, patients. They spend their time in workshops, in internships, and in sports and artistic activities proposed inside and outside of the establishment. In this sense they are both actors in terms of engaging actively as patients, but also actors in terms of their artistic projects or recreational activities. In this way, the double entendre we mentioned in Chapter's 1's English translation of *patient acteur* to mean "patient actor" takes on a new meaning, as patients are allowed to be social beings capable of engaging in play.[804]

The Teppe is also space which initiates action, as the activities of the personalized project take place within and outside of the establishment. It therefore is a habitable space rather than just one that shelters or protects.[805] The hospitality space permits an environment in which passive patients (such as those who have been overprotected), can become active.[806] They are no longer *just* patients that receive healthcare services: they are also workers, artists, or friends of fellow patients. They sell the fruits they make to healthcare personnel; they offer their artworks to their friends or their doctor; they participate in sports activities within and outside of the establishment. The personalized project takes of all of these factors into account and enables patients to become patients,

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[803] This includes changing Band-Aids or other minor healthcare acts in the service. For more complicated medical care, patients are transferred to the medical block, in which professionals do wear the white coat when interacting with patients. I would like to thank Dr. Petit for this clarification.

[804] Nussbaum's Capability 9 is, *"Play. Being able to laugh, to play, to enjoy recreational activities."* Nussbaum, M.C., 2011. Creating capabilities the human development approach. Orient Blackswan, New Delhi. p. 34.

[805] Bouaniche, Arnaud. *« L'espace hospitalier à l'épreuve de la naissance. »* In: Barrère, C., 2019. *Cahiers thématiques: architecture et paysage, conception, territoire, histoire, matérialité.* p. 134.

[806] *Ibid.*, p. 135.

but also something other than patients, both for themselves and for healthcare providers. We saw in Christophe's story at the beginning of this chapter that he first introduced himself as a wood worker, rather than a patient; the hospitality space enables him to become something other than a patient in most temporalities, even while taking into account his complex healthcare needs within the hospital environment.

The line, however, is clear between healthcare providers and patients: both are requested to respect one another (this does not always work, but it is the basis of the relationship). To demarcate this line, the healthcare personnel continue to use the word "patient" when they speak about patients in a general manner or as a group, instead of "user" or simply "person" to remind the patients, but also the personnel, that they are in a hospital and that both have rights, but also responsibilities, toward one another. However, patients are mostly known by their first names, and in turn the patients address their nurses and social educators by their first names.[807] There is a familiarity and camaraderie among fellow patients, but also among patients and their healthcare team.

In turn, the common spaces of the hospital are designed for interaction between fellow patients and staff. In the service of St. Joseph for example, which is considered at the facility as a cocoon where patients will find a warm space when they first leave their family homes (where they are often overprotected), there are couches, a bar that opens each evening for all the patients and residents, and even old pinball games with a nurse and a doctor as the main protagonists. While the staff room is not "common," it is available to all patients with a simple knock on the door. There are few appointments to make; the spatial proximity of healthcare providers to patients allows these providers to respond immediately to needs and requests. This capability to respond is both due to the structure and to its space of interaction, which permit this immediate response to patients' needs.[808]

For patients, the Teppe is a residence, one in which they can stay several months, several years, or even their whole adult lives. In turn, many healthcare providers have passed their entire professional lives at the Teppe. In a space which does have to follow a pay-per-use model, but instead is formulated in terms of a personalized project, patients and healthcare providers are able to take the time needed to develop, implement, and

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[807] Patients and doctors however address each other by their surnames, which is perhaps a reflection of not being a part of daily life in the service and/or in order to show respect for their doctor/patient.

[808] As Bouaniche says, a hospital space is one in which the space can respond. By this he means response in terms of the dialogue between two human beings and the qualities of the spaces which allow such a response between the two. Bouaniche, Arnaud. *« L'espace hospitalier à l'épreuve de la naissance. »* In: Barrère, C., 2019. *Cahiers thématiques: architecture et paysage, conception, territoire, histoire, matérialité.* p. 132.

modify the healthcare plan to ensure its success. They do so in a hospital environment that allows hospitability for *both* healthcare providers and their patients.

The Teppe is not a perfect institution; it is one, however, in which the epistemic contributions of patients are necessary for achievement of the healthcare plan, where patients see themselves as workers, artists, friends, *and* patients; and one in which healthcare providers see the patient for whom they work as all of these things. The spatial and architectural hospitalities of the structure help ensure that the healthcare plan designed for the patient takes into account their life projects, providing the means for them to become actors. The patient life empowerment approach at the Teppe helps patients to go to the limits of their capabilities, in their work, leisure, and relationships, and it is a space where they can learn *with* and *toward* others, without fear.

Conclusion

This thesis was an endeavor to produce a patient-developed approach of patient empowerment. Several new approaches have been proposed, notably, the patient life empowerment and family life empowerment approaches. These approaches have integrated the epistemic contributions of patients to understand what they need from healthcare providers and persons outside the healthcare relationship (families and society) to live well with their disease. By first taking a failure-first methodological approach, we have identified how others are currently harming these patients both within and outside the healthcare relationship and what they can do to support them to live better with their diseases.

These approaches move the starting point and the focus of patient empowerment to the patient and what they are seeking in their healthcare and in their overall lives. By soliciting patients' views on empowerment, we have come to understand that what patients want and need from empowerment is the ability to gain control of their lives, to be able to plan their life projects *with* and *toward* others. Thus adherence as an outcome cannot be the only criteria for patient empowerment, nor can autonomy. How much others can create a supporting environment for persons with disease has shown us just how fundamental these relationships are to patients' capabilities to live well and just how harmful they can be due to emotions such as fear.

Our patient life empowerment approach involves a wider responsibility for society, and moves us beyond individual responsibilities for the doctor or for the patient to produce some result called empowerment. Healthcare providers are often frustrated by their limited role in healthcare outcomes, due to various factors they cannot control or help with in the patient's life. In turn patients remain frustrated by how much their illness is affected by their environment, no matter how well they adhere to their treatment plan or find individual strategies to manage their disease. Our definition of patient life empowerment brings us both toward a more realistic and inclusive definition of patient empowerment, as one that involves others in helping the person to flourish. Most importantly, our approach shows how much we will need to continue to solicit and listen to the epistemic contributions of patients and their families in these discussions. It is only then that we can claim that the paternalistic model of healthcare has finally ended.

We have highlighted what the patient and family life empowerment approaches might look like in public policy and in activities organized by patient associations. However, given the economic realities of healthcare today, it is recommended for future work to identify the potential cost savings that a patient life empowerment approach might encompass, which might make it a feasible goal for healthcare and other institutions. In our approach, we are moving beyond a cadre focused solely on the doctor's or the patient's responsibilities. We are therefore moving away from a slippery slope — every more present in healthcare discussions — seeking to make the patient solely responsible for healthcare outcomes. With our approach, we are integrating society into these outcomes and our joint responsibilities into realistically helping the patient to be healthy with their disease. Right now, potential savings related to patient participation in healthcare decision-making is frequently limited to achieving healthcare outcomes under a limited economic model, such as reduced hospital admissions. Our patient life empowerment approach, however, sees the patient's well-being in a wider framework of the patient's whole life and their abilities to flourish within it. Thus our approach will involve a wider cadre of evaluation. Notably, we will include in our approach the significant social costs of underemployment and non-employment of patients to understand how much these failures cost the individual and wider society.

It is recommended for future research to see to what extent the patient life empowerment approach will be pertinent to other chronic and acute diseases, and what differences between epilepsy and other diseases might be identified. This will help strengthen and further develop the patient life empowerment approach and its specific needs for individual patients and their families, as well as for specific institutions. Epilepsy is a borderline case, as it involves significant social constraints as well as the need for others when the body loses control. Martha Nussbaum advocates in her capabilities approach that achieving capabilities are not just for the "well off," indeed they are for everyone, and it is our responsibility in society to assist those who need more help to get to the threshold. We have highlighted here what blocking factors have kept our particular patients from flourishing; other diseases may have other blocking or enabling factors which remain to be explored. Our approach seeks to move toward patient life empowerment for *all* patients. Therefore we propose a flexible approach to allow modification and new conceptualizations for new groups and individual patients.

Another research area which could be developed out of this thesis would be to use and further develop the method *with* emotions in order to identify specific emotions and

their importance in the healthcare relationship and for patients' relationships in society. Fear is a particularly strong emotion in our research, but identifying other emotions such as shame, anger, happiness or surprise, may give us new reflections for the patient life empowerment approach, as well as ways to improve the healthcare relationship for individual patients and their doctors.

This thesis also contributes to the development of the blossoming field of epistemic injustice, which is only 12 years old, and can be further developed in the healthcare field. Our method *with* emotions has contributed methodological tools to formulations of non-ideal theories[809] as suggested by the field of epistemic injustice. This thesis showed the need to further develop new methods to solicit the epistemic contributions of patients. The research methods developed and used here suggest that patients' and families' views may be significantly different from healthcare providers, healthcare institutions, and health economists' perspectives. This research makes clear the differences between these perspectives. It remains urgent to develop these and new methods to work *with* patients, rather than speaking through them. We have not fully exited the paternalistic model, for all of our rhetoric otherwise. Research in this field is still lacking in both its breadth and depth and more research in this direction is needed to understand the patient's and family members' perspectives in healthcare decision-making.

Our contribution includes the development of several new methods for fieldwork in philosophy, which are called the method *with* emotions and the method *with* capabilities. In particular, the methods developed show new ways and means to solicit the epistemic contributions of research participants. We believe these methods can also be mobilized in other disciplines to move toward greater epistemic partnership. Fields such as anthropology and sociology are increasingly turning toward philosophy to find new ways and means to explore their subjects. The methods outlined here give suggestions of ways to work in greater epistemic partnership with patients, which may inspire methodological development in other disciplines. In addition, as emotion research is increasingly being viewed as an opportunity rather than a constraint in these disciplines, our method *with* emotions in inspiration of Martha's Nussbaum's conceptualizations of emotions gives new ways to analyze these emotions for fieldwork approaches in other disciplines.

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[809] According to Robeyns, much work still needs to be done on developing non-ideal theories, especially in order to provide a bridge between ideal theories and action design and implementation. See: Robeyns, I., Department of Philosophy, Florida State University, 2008. *Ideal Theory in Theory and Practice*: Social Theory and Practice 34, p. 362.

Through the method *with* emotions, our research gives weight to the value of emotions in healthcare and proposes solutions for healthcare providers, patients, and families, when they recognize these emotions as saying something important about their flourishing. One of our aims in this thesis was to give value to emotions, to show that they are not something to be avoided, but that they show us something of importance to the persons experiencing them. While the "emotional turn" has been elaborated in academic literature, it was clear throughout our fieldwork the ambivalent relationship that healthcare providers had to their own emotions in their professional practices. Despite recognition that helping patients with their emotions is an important means of helping them live better with their diseases, emotions continue to be described as negative, leading healthcare professionals away from achieving performance. As Nussbaum has shown, emotions form important parts of our judgments about our world. It is time to take them seriously.

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Appendices

Appendix A: Definitions of Epilepsy and Related Terms

This appendix will highlight several definitions of epilepsy and related terms. Most of the clinical definitions highlighted here have been established through working groups at the International League Against Epilepsy.[810] These are currently the definitions which have achieved the most international consensus; however, debates over these classifications (and clinical practice guidelines resulting from these classifications) are ongoing. In this Appendix, we have also included several common definitions which are frequently used to explain various terms (such as SUDEP) to a wider audience.

Seizure	A transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain.[811]
Epilepsy	*2014 – current definition:* *A disease of the brain defined by any of the following conditions*: 1) At least two unprovoked (or reflex) seizures occurring more than 24 hours apart. 2) One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years. 3) Diagnosis of an epilepsy syndrome.[812]
	An earlier definition from 2005 reads: Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological, and social consequences of this condition.[813]

[810] Guidelines // International League Against Epilepsy [WWW Document], n.d. URL https://www.ilae.org/guidelines (accessed 8.30.19).

[811] Fisher, R.S., Boas, W. van E., Blume, W., Elger, C., Genton, P., Lee, P., Engel, J., 2005. *Epileptic Seizures and Epilepsy: Definitions Proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).* Epilepsia 46, 471.

[812] Fisher, R.S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J.H., Elger, C.E., Engel, J., Forsgren, L., French, J.A., Glynn, M., Hesdorffer, D.C., Lee, B.I., Mathern, G.W., Moshé, S.L., Perucca, E., Scheffer, I.E., Tomson, T., Watanabe, M., Wiebe, S., 2014. *ILAE Official Report: A practical clinical definition of epilepsy.* Epilepsia 55, p. 477.

[813] This definition has now been replaced in order to give more statistical clinical practice guidelines (however at the expense of the emphasis on the social and psychological consequences of the condition). For the previous definition, see: Fisher, R.S., Boas, W. van E., Blume, W., Elger, C., Genton, P., Lee, P., Engel,

Stabilization	Seizures are said to have been stabilized when AEDs or other treatments succeed in stabilizing the electrical activity of the brain. This can mean that the patient will have no further seizures, or that seizures are relatively "stabilized" (i.e. they have less seizures, or less severe seizures than before treatment).
Aura	A focal seizure wherein a patient retains awareness and describes motor, sensory, automatic, or psychic symptoms[814]
Seizure types	Focal onset, generalized onset, unknown onset[815]
Epilepsy types	Focal, generalized, combined generalized and focal, unknown[816]
Etiology	Structural, genetic, infectious, metabolic, immune, unknown[817]
Syndrome	A cluster of features incorporating seizure types, EEG, and imaging features that tend to occur together. A syndrome does not have a one-to-one correlation with etiological diagnosis and is used to guide clinical management of the disease.[818]
Refractory epilepsy	The failure of adequate trials of two tolerated and appropriately chosen and used AED schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom."[819] *Refractory epilepsy* is also known as drug-resistant, uncontrolled, or intractable epilepsy.
Severe epilepsy	Epilepsies in which the seizures and associated difficulties significantly reduce the possibility for the person to mobilize their competences (mental, cognitive, psychic, sensory, motor)[820]

J., 2005. *Epileptic Seizures and Epilepsy: Definitions Proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).* Epilepsia 46, p. 470.

[814] Stafstrom, C.E., Carmant, L., 2015. *Seizures and Epilepsy: An Overview for Neuroscientists*. Cold Spring Harbor Perspectives in Medicine 5, a022426–a022426.

[815] For the types of seizures seen in these seizure types, please see: Fisher, R.S., Cross, J.H., D'Souza, C., French, J.A., Haut, S.R., Higurashi, N., Hirsch, E., Jansen, F.E., Lagae, L., Moshé, S.L., Peltola, J., Roulet Perez, E., Scheffer, I.E., Schulze-Bonhage, A., Somerville, E., Sperling, M., Yacubian, E.M., Zuberi, S.M., 2017. *Instruction manual for the ILAE 2017 operational classification of seizure types*. Epilepsia 58, p. 524.

[816] Scheffer, I.E., Berkovic, S., Capovilla, G., Connolly, M.B., French, J., Guilhoto, L., Hirsch, E., Jain, S., Mathern, G.W., Moshé, S.L., Nordli, D.R., Perucca, E., Tomson, T., Wiebe, S., Zhang, Y.-H., Zuberi, S.M., 2017. *ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology.* Epilepsia 58, p. 515.

[817] *Ibid.*, p. 515

[818] *Ibid.*, p. 515

[819] Kwan, P., Arzimanoglou, A., Berg, A.T., Brodie, M.J., Allen Hauser, W., Mathern, G., Moshé, S.L., Perucca, E., Wiebe, S., French, J., 2009. *Definition of drug resistant epilepsy: Consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies: Definition of Drug Resistant Epilepsy*. Epilepsia 51, p. 1069.

[820] Oguz, O., Fourdrignier, M., Jacquemaire, A., Perret, F., FAHRES. *Lutter contre la souffrance psychique sur ajoutée chez les personnes en situation de handicaps rares à composante épilepsie sévère. Quels enseignements de l'approche interpersonnelle sur les récits de vient leurs moments clés, pour créer de véritable rencontres entre familles et professionnels ?* p. 10.

SUDEP	The unexpected, witnessed, or unwitnessed, death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, drowning or trauma, with no toxicological or anatomic cause for death found post-mortem."[821]
Status epilepticus	A commonly used definition is: A neurologic and medical emergency manifested by prolonged seizure activity or multiple seizures without return to baseline. It is associated with substantial medical cost, morbidity, and mortality.[822] According to the current ILEA definition (2015 – present): status epilepticus is a condition resulting either from the failure of the mechanisms responsible for seizure termination or from the initiation of mechanisms, which lead to abnormally, prolonged seizures (after time point t_1). It is a condition, which can have long-term consequences (after time point t_2), including neuronal death, neuronal injury, and alteration of neuronal networks, depending on the type and duration of seizures.[823]
Kindling	A metaphor which shows that the increase in seizures is similar to the way burning twigs can produce a large fire. A small seizure (or any seizure for that matter) can increase the likelihood that more seizures will occur, or in other words, repeated seizures lower the threshold for more seizures to occur. [824]

[821] Keddie, S., Angus-Leppan, H., Parker, T., Toescu, S., Nash, A., Adewunmi, O., Liu, R., 2016. *Discussing sudden unexpected death in epilepsy: Are we empowering our patients? A questionnaire survey.*
[822] Pichler, M., Hocker, S., 2017. *Management of status epilepticus*, in: *Handbook of Clinical Neurology*. Elsevier, p. 131.
[823] Fisher, R.S., Boas, W. van E., Blume, W., Elger, C., Genton, P., Lee, P., Engel, J., 2005. *Epileptic Seizures and Epilepsy: Definitions Proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).* Epilepsia 46, p. 471.
[824] Bertram, E., 2007. *The Relevance of Kindling for Human Epilepsy*. Epilepsia 48.

Appendix B: Research Methods

This appendix will highlight the research methods used for this project, including the method *with* emotions, the method *with* capabilities, and forum theatre.

1. Method *with* Emotions

Stages	**Content**
1. ***Focused ethnography stage***	Pilot testing to clarify what ideas emerge during discussions among patients and healthcare providers. Focused ethnography permits rich contextualization of the specific site and actors at each site. Method used included paying attention to recurrent words expressed by research participants to understand when patients used the words/why to better understand recurrent and emerging themes.
2. ***Interview stage***	In-depth interviews of patients and healthcare providers to verify and further develop themes identified in the focused ethnography stage, as well as identify new themes. *Questions for patients*: Question 1: Please tell me about your epilepsy? Question 2: What do you understand by patient empowerment? *Questions for healthcare providers*: Question 1: please tell me about your work at the institution? Question 2: What do you understand by patient empowerment?
3. ***Toward greater epistemic partnership***	Development of a theatre play with patients to allow epistemic productions between research participants/researcher; also used as a way to develop new themes and to appropriate the research in a personal way (taking the place of actors)
4. ***Seeking convergence***	Verification of the salience of these themes across sites to identify common themes, notably in different healthcare environments
5. ***Analysis***	Analysis of research findings through thematic analysis. Final analysis includes understanding why and how patients have expressed emotions; what kinds of actions these emotions have results in; if there is a distortion or intensity related to the emotion which may signal its importance to the person concerned. This final stage of the method aims to understand these emotions through the perspective of the patients' flourishing in order to understand the impact of these emotions on their abilities to "live well" with their diseases in society.

2. Method *with* Capabilities

Stages	**Content**
1. ***Focused ethnography stage***	Pilot testing to clarify and illuminate initial reviews of international literature. Method used included paying attention to recurrent ideas expressed by research participants when they discussed their healthcare or relationships with their doctors.
2. ***Interview stage***	In-depth interviews of patients and healthcare providers to solicit understandings of patient empowerment, notably by asking directly both actors what they understand by patient empowerment and about their overall lives with epilepsy.
3. ***Analysis***	Analysis of research findings through thematic analysis to define what patients defined as important to "live well" and organization into themes based upon Martha Nussbaum's capabilities list but with specifications, directions, and originalities directly coming from patients themselves. Conversational analysis to note when patients described themselves in active or passive ways, notably in their abilities to plan their lives, including in their healthcare, to understand in what ways and where patients seek agency (i.e. either in their overall lives or specifically in their healthcare plans)

3. Theater Play Production (French)

Personnages:
Pierre : *personne épileptique*
Suzanne : *sa sœur, ou sa femme (soutien E)*
Emma : *cousine de E et S, travaillant dans le secteur médical. (Oppresseur)*
Corinne : *collègue de E (Oppresseur secondaire)*
Natacha : *collègue de E (Oppresseur Principal)*

Contexte : *C'est l'anniversaire de Pierre. Toute sa famille, les amis, les collègues sont invités. Table, verres, boissons, petits biscuits apéro, éventuellement guirlande, ballons…Pierre vient de faire une crise. Sa sœur l'a installé dans un fauteuil (transat). Arrive Emma, Suzanne va l'accueillir.*

Suzanne - Bonjour Emma ! Comment vas-tu ?

Emma - Oh, toujours pressée, stressée, à l'hôpital, je n'ai pas un moment de répit. Il y a plein de collègues malades en ce moment et en plus de mon emploi du temps hyper chargé, il faut que je me charge du boulot des autres. Pfff ! Si ça continue, ce sera moi la patiente bientôt !

Suzanne - Oui, j'ai entendu aux infos la situation du personnel hospitalier … Pas drôle … Mais tu vas voir, ce soir, c'est la fête ! On va se charger de te détendre ! … Tu arrives la première, tu es toujours aussi ponctuelle ! Tu veux boire quelque chose ?

Emma – Volontiers. Qu'est-ce que tu me proposes ?

Suzanne – Martini, Vin doux, ou si tu aimes plus fort, Whisky …

Emma – Un vin doux s'il te plaît. Et ton frangin ?… Où est-il, au fait ?

Suzanne – Il vient de faire une crise il y a une demi-heure. Il se repose là.

Emma – Ah zut … Ce n’est pas de chance, juste pour sa soirée d'anniversaire !

Emma *se dirige vers Pierre.*

Emma – Bon anniversaire, mon vieux … Ça ne va pas fort, on dirait …

Pierre – Oui, je suis un peu fatigué maintenant, mais ça va aller.

Emma – Et dis-moi, tu prends bien tes médicaments ?

Pierre – Oui, oui, bien-sûr. Mais j'ai des effets secondaires (à voir lesquels)

Emma – Oui, mais bon … C'est le prix à payer, hein, quand on est épileptique ! Tu es sûr que tu prends la bonne posologie ?

Pierre *veut parler, mais* Emma *lui coupe la parole.*

Emma – Tu m'avais dit qu'on avait augmenté les doses, pourtant.

Pierre – Oui, oui.

Suzanne *vient vers eux avec le vin doux pour Emma.*

Suzanne – Tiens ton verre.

Emma – Merci Suzanne.

Suzanne – Tu as soif, Pierre ?... Attends, je vais aller te chercher un verre d'eau.

Emma – Tu les prends bien à heure fixe ?

Pierre – Oui …

Emma – Et tu as peut-être pris de l'alcool, ce soir ? Tu sais que c'est formellement interdit aux épileptiques !

Pierre – Non, je (n'en ai pas p …)

Emma – Pas d'alcool, pas de baignade sans surveillance, ne plus conduire, surtout. Tu sais que tu peux avoir une crise n'importe quand, donc, fais attention à toi !

Pierre – Euh…

Emma – Bon, il faut que tu te reposes maintenant.

Pierre – Oui, je suis fatigué.

Suzanne *revient avec le verre d'eau.*

Pierre – Merci.

Suzanne – Il me semble que depuis qu'il fait de la méditation, ses crises se sont espacées quand-même. Ca fait déjà un moment que tu n'en avais plus eu, hein, Pierre ?

Pierre – Oui, ça me réussit plutôt bien je trouve.

Emma – C'est n'importe quoi ! La méditation pour soigner l'épilepsie, laisse-moi rire ! C'est un truc pour babacools, ça ! Attention, Suzanne, ne l'entraîne pas sur cette pente-là. Un de ces jours, il ne prendra plus ses médicaments avec tes conseils foireux, et là, il va être mal !!!

Pierre – Mais (moi je te dis que ça me fait du bien !)

Emma – Et puis, tu sais, attention, hein, ces gens-là sont au mieux de doux rêveurs et au pire de dangereux gourous !

Pierre – Oui, mais (je sais ce que je fais quand même!)…

Suzanne – Mais il n'a pas arrêté son traitement. Il pratique la méditation, il prend en plus de la valériane, il (a beaucoup moins de crises)…

Emma – Stop, Suzanne ! C'est de la poudre de perlimpinpin tout ça ! Je m'inquiète vraiment pour sa santé ! Et c'est dangereux de croire (tous ces charlatans)...

Suzanne – Mais non !…

Suzanne *s'énerve, puis aperçoit Nathalie et Corinne qui viennent d'arriver et plante là* Emma*, qui s'éloigne en maugréant.*

Suzanne – Ah ! Bonsoir Corinne, bonsoir Nathalie !

Corinne et Nathalie – Bonsoir Suzanne !

Elles se font la bise.

Nathalie – Alors, il se cache où, Pierre, qu'on aille lui souhaiter son anniversaire ?

Corinne – Oui, on a aussi un p'tit cadeau pour lui.

Suzanne – Il vient de faire une crise juste avant et du coup, il se repose sur le fauteuil, là-bas…

Nathalie – Ah ! Sacré Pierre ! Il en rate pas une pour se faire remarquer !

Corinne – Ha ! Ha ! Ha ! Eh, Pierre !

Elles se dirigent vers Pierre.

Nathalie – Salut Pierre ! Bon anniversaire !

Corinne – Bon anniversaire !

Pierre – Merci.

Nathalie – Alors, tu te la coules douce, il paraît ? Tu te lèves même pas pour nous saluer ?

Corinne – Ha! Ha! Ha !

Suzanne *(en souriant)* – Laissez-le tranquille … Qu'est-ce que vous buvez ? Vin doux ? Martini ? Whisky ?...

Corinne – Un Martini pour moi. Merci.

Nathalie – Un Whisky, Suzanne, s'il te plaît. Eh, Pierre, tu devrais pas autant boire, toi, ça te réussit pas on dirait !

Corinne – Ha! Ha ! Ha ! Après, tu roules sous la table !

Pierre – Laissez-m… (moi tranquille)

Suzanne – Et voilà ! Whisky pour toi et Martini pour toi …

Nathalie et Corinne – Merci.

Suzanne *va rejoindre* Emma. *Sert des petits biscuits apéro, discute avec elle ...*

Nathalie – Non, sérieux, tu restes trop longtemps à regarder les écrans, la télé, l'ordinateur … Moi, si j'étais à ta place, j'arrêterais. T'as qu'à téléphoner, au lieu d'envoyer des emails à tout bout de champ comme ça. C'est mauvais, moi je te dis.

Pierre *se prend la tête. Il est visiblement fatigué.*

Nathalie – Et arrête de prendre des poses !

Corinne – C'est un bon comédien !

Suzanne *revient avec des biscuits apéro.*

Nathalie – Tu sais, Pierre, je devrais pas te le dire, mais au bureau, tout le monde pense que tu es un glandeur fini, à force de prendre des arrêts maladie !

Corinne – Oui, en plus tu as déjà des horaires aménagés, alors …

Suzanne – Mais il se plaint justement qu'on lui donne tout le boulot le plus ingrat, le plus fatiguant, comme il reste moins longtemps que vous, c'est pas (réglo, ce que vous faites)

Nathalie – Et le trou de la sécu, qui c'est qui va le combler, hein ? Sûrement pas toi, ça non ! Faut savoir être responsable dans la vie, Pierre ! Je te dis ça pour ton bien, parce que au bureau, les autres ils en ont marre de tes absences.

Corinne – Oui, même quand tu es présent, tu en as, des absences !

Corinne *et* Nathalie *rigolent.*

Suzanne – Mais arrêtez, vous n'y comprenez rien !

Corinne – Ouais, c'est vrai, on exagère, là !

Suzanne *retourne vers* Emma.

Nathalie – Mais non, moi, je te dis que c'est psychologique, tout ça. Sors un peu de chez toi, remue-toi, tu verras, ça ira mieux.

Corinne – Ben oui !

Nathalie *et* Corinne *s'éloignent un peu, vont vers* Emma. Suzanne *fait les présentations.*

Suzanne – Emma, je te présente Corinne et Nathalie, collègues de bureau de Pierre. Emma, notre cousine.

Corinne et Nathalie et Emma : Enchanté !

Suzanne *va vers* Pierre.

Corinne – Et bien, il est dans un drôle d'état, Pierre !

Emma – Oui, ça tombe mal, juste le jour de son anniversaire …

Nathalie – Moi, je crois qu'il devrait être enfermé …

Emma – Comment ça ?

Nathalie – Dans un hôpital psychiatrique ! Il tourne pas rond, nous, on est ses collègues de travail et parfois, on a l'impression qu'il déraille, vraiment. Il dit n'importe quoi, il délire, quoi ! Ces gens-là, on les enferme !

Corinne – Peut-être pas jusqu'à l'enfermer, quand même …

Emma – Mais ce n'est pas ça (c'est une affection neurologique)…

Nathalie – Même qu'autrefois, on croyait qu'ils étaient possédés, ceux qui (il mime quelqu'un qui convulse), moi j'y crois pas, mais y a peut-être quand même du vrai là-dedans ...

Corinne – Ah oui ?

Pierre *les rejoint, soutenu par* Suzanne.

Emma – Ah ! Tu te sens mieux ?

Pierre – Et bien …

Nathalie – Et c'est pas contagieux, ton truc, là ? Non, parce que je me suis un peu renseignée, sur internet et aussi des copains. Ils m'ont dit que ça pouvait s'attraper ...

Corinne – Ah oui, c'est contagieux ? Oulala !… Moi, j'attrape tout ce qui passe en ce moment ! … Tiens au fait, ton cadeau …

Elle lui jette son cadeau et s'en va en mettant son foulard sur la bouche.

FIN

Theatre Play Production (English)

Characters:
Pierre – Person with epilepsy
Suzanne – His sister
Emma – Pierre and Suzanne's cousin, working in the medical sector
Corinne – Pierre's colleague
Nathalie – Pierre's colleague

Context: *It's Pierre's birthday. All his family, his friends, and his colleagues are invited to celebrate. Pierre has just had a seizure. His sister put him in an armchair in order to rest. Emma arrives and Suzanne goes to welcome her.*

Suzanne – Hello Emma! How are you?

Emma – Oh, stressed as usual at the hospital, no time to catch my breath. There are lots of colleagues who are sick right now and also my schedule is super full. I even have to take care of other people's work. If this continues, it will be my turn to be the patient!

Suzanne – Yes I've heard from the news the situation of hospital personnel…not fun…but don't worry, tonight, we are going to celebrate! We will help you relax. You're the first one to arrive, you are always punctual! Do you want to drink something?

Emma – Yes please. What do you have?

Suzanne – Martini, wine, or if you would like something a bit stronger, whisky…

Emma – A glass of wine please. And Pierre? Where is he?

Suzanne – He just had a seizure half an hour ago. He's resting.

Emma – Ah darn…he's unlucky, just in time for his birthday party!

Emma *goes over to* Pierre.

Emma - Happy birthday old guy…you're not doing very well, it seems …

Pierre – Hello Emma, my dear cousin. Yes, I am a bit tired right now, but it's going to be all right.

Emma – Tell me, you do take your medicine, right?

Pierre – Yes, yes of course. But I have side effects (I have a headache, I'm always tired…)

Emma – Yes but…it's the price to pay to have less seizures! Are you sure you take the right dose as the doctor prescribed?

Pierre *wants to talk, but Emma cuts him off.*

Emma – You told me that they increased the dosage, actually.

Pierre – Yes, yes. At the last consultation at the neurologist's, I…

Suzanne *comes up to them with the wine for* Emma.

Suzanne – Here's your wine.

Emma – Thank you Suzanne.

Suzanne – Are you thirsty, Pierre?... Wait just a minute, I'm going to get you a glass of water.

Pierre – Yes, thank you.

Emma – Are you taking them at the right time?

Pierre – Yes…

Emma – Did you drink some alcohol tonight? You know it's forbidden for epileptics!

Pierre – No, I didn't…

Emma – No alcohol, no swimming without surveillance, and especially no driving. You know you can have a seizure at any time, so be careful!

Pierre – Umm…

Emma – Okay, you should rest now.

Pierre – Yes, I'm tired.

Suzanne *comes back with the glass of water.*

Pierre – Thank you.

Suzanne – You know, it seems that since he practices meditation, his seizures have been less frequent. You've been doing that for quite a while, right, Pierre?

Pierre – Yes, it works quite well for me, I think.

Emma – What! Meditation for epilepsy, what a joke! That's for hippies! Be careful, Suzanne, don't lead him down that path. One of these days, he won't take his medicine because of that kind of advice, and he will regret it!!!

Pierre – But I think that (it does me good!)

Emma – And also, you know, be careful, those guys are at best dreamers and at worst dangerous gurus!

Pierre – Yes, but I know (what I'm doing, you know!) …

Suzanne – But he didn't stop his treatment. He practices meditation, he also takes valerian, and he (has a lot less seizures)…

Emma – Stop, Suzanne! Stop with those fake magical cures! I'm really worried for his health! It's dangerous to believe (all of those charlatans) ...

Suzanne – No, c'mon!!…

Suzanne *is annoyed but sees Nathalie and Corinne who have just arrived and leaves* Emma *alone, who goes away mumbling to herself.*

Suzanne – Hello Corinne, hello Nathalie!

Corinne et **Nathalie** – Hello Suzanne!

They greet each other.

Nathalie – So where's Pierre hiding? We want to wish him a happy birthday!

Corinne – Yes, we also have a small gift for him.

Suzanne – He just had a seizure, so he's resting over there.

Nathalie – Ah, that Pierre! He never misses an opportunity to be seen!

Corinne – Ha! Ha! Ha! Hey, Pierre!

They go over toward Pierre.

Nathalie – Hi Pierre! Happy birthday!

Corinne – Happy birthday!

Pierre – Thank you.

Nathalie – So, you're hanging loose, it seems! You won't even get up to greet us?

Corinne – Ha! Ha! Ha!

Suzanne *(smiling)* – Let him be … So, what are you drinking? Wine? Martini? Whisky?...

Corinne – A martini for me, thanks.

Nathalie – a whisky please, Suzanne. Pierre, you shouldn't drink even a drop of alcohol, it doesn't do you any good it seems!

Corinne – Ha! Ha! Ha! Yes, afterward you are rolling under the table!

Pierre – Leave me (alone)

Suzanne – Here I am! Whisky for you and a martini for you…

Nathalie and **Corinne** – Thank you.

Suzanne *stays with Nathalie and Corinne.*

Nathalie – No, but seriously, you stay too much time looking at screens, at television, at the computer…if I were in your shoes, I would stop. It's bad for you.

Pierre *puts his head in his hands. He looks very tired.*

Nathalie – And stop taking so many breaks!

Corinne – He's a good comedian!

Suzanne *comes back with some pretzels.*

Nathalie – You know, Pierre, I shouldn't say it, but at work, everyone thinks that you're a slacker, from taking all those sick days!

Corinne – Yes, especially because you have special hours…

Suzanne – But he's always complaining that they give him the worst and most tiring job, as he stays less time at the office then you (it's not normal what you are doing).

Nathalie – And the massive hole in public finances, who is going to repair it, hmmm? For sure not you! You need to learn to be responsible in life, Pierre! I'm saying that for your own good, because at work, the others are tired of your moods and your absences.

Corinne – Yes, even when you are present, you have absences!

Corinne *and* **Nathalie** laugh.

Suzanne – Stop it already, you don't understand anything!

Corinne – Sorry, yes, it's true, we're taking it too far!

Suzanne *goes back to* Emma.

Nathalie – But I'm telling you, it's purely psychological, all of that stuff. Get out a bit more, you will see, it will do you good.

Corinne – Of course!

Nathalie and **Corinne** *go away from Pierre and toward* Emma. Suzanne *introduces them.*

Suzanne – Emma, this is Corinne and Nathalie, colleagues of Pierre. Emma is our cousin.

Corinne and **Nathalie** and **Emma** – Nice to meet you!

Suzanne *goes towards* **Pierre**.

Corinne – Well, he's in a strange state, that Pierre!

Emma – Yes, he's unlucky, on his birthday…

Nathalie – I think it's more of a mental problem, those seizures…

Emma – What?

Nathalie – Well, it's obvious that something is not right. We're his colleagues, we see him everyday at work, and sometimes, we have the impression he's crazy. He says weird things…and then he doesn't even remember saying them! It's some kind of delusion. When it's like that, you should go see a psychiatrist. There are hospitals for that kind of thing.

Corinne – Now wait a minute, you're exaggerating a bit…

Emma – But it's not that (it's neurological)…

Nathalie –You know before, we thought they were possessed, those…*(she mimics a convulsion).* Personally, I don't believe it, but there's maybe some truth in it…

Corinne – Really?

Pierre *rejoins them, helped by* Suzanne.

Emma – Ah! Do you feel better?

Pierre – Well …

Nathalie – Ah, you see, when you want to….

Nathalie – But it's not contagious…your thing? Because I looked it up, on the Internet and I also asked some friends. They told me it could be contagious...

Corinne – Really, it's contagious? Oh no… I catch anything and everything that's going around. Here, Pierre, your gift…

She throws the gift at Pierre and turns away, putting her hands over her mouth.

END

Appendix C: Narrative Cases

This appendix relates the full narrative cases constructed from interviews. Five narrative cases from the Teppe and five narrative cases from Huashan Hospital, in Shanghai, China, are highlighted in this appendix. These cases, along with others, were weaved into the thesis in various ways. Our aim in highlighting these cases is to show the individual trajectory of each person's story with epilepsy, but also to highlight how similar stories can be found across countries in lived experiences of the disease. These cases have been included instead of the retranscriptions of the interviews as they both allow a more holistic understanding of the life trajectories of these patients, as well as allowing for greater anonymity for the participants involved. In these narrative cases, some personal details, in particular names, have also been changed to favor greater anonymity.

5 Narratives Cases of Patients at the Teppe (Tain-l'Hermitage, France)

Patient 1 - Christophe*: my first interview at the Teppe was with Christophe, a young 22-year old man who had volunteered to be interviewed following my introduction to the patients in the service. He had a small bandage above his eye, as he had a seizure during the weekend when he had fallen on the head of the dresser. The social educators and nurses had been discussing his case during the morning meeting as the number of his seizures had been increasing lately, leading to terrible falls, cuts, and bruises. They were worried about him and wondering if he should readjust his medication or his VNS stimulator. The interview took place in a meeting room adjacent to the hospital residence, in earshot of the healthcare team in case of an emergency.*

I started the interview by asking Christophe to tell me about himself and his epilepsy. He said that it was soon going to be a year since he had been at the Teppe. Introducing himself as a worker rather than a patient, he said that was now working in a wood workshop, that he was head of the production line, and that he helped assemble and unpack wood to be used later by the other workers. He continued by telling me about his family, especially his sister, and the fact that he had "done" other medical-social centers before coming to the Teppe.

He told me that he had refractory epilepsy and that it was annoying. He has done practically everything to try and stabilize his epilepsy: operations, EEGs, VNS…as I did not know that much about the VNS stimulator, he explained to me its effects, how it was different for every person. For him, it gave him a sort of "hot shot" but otherwise did not bother him. Indeed the VNS is probably the only thing that has really worked for him in his long healthcare journey: he no longer has the small seizures he used to have, and the bigger seizures tend to last less time than before and to be less severe. Even better, while he may fall during a seizure, it will not happen instantly like before, which gives other people time to react and to help put him to a safe position.

He says that his epilepsy started at the age of 6 when he was in a water park, inside a water slide. It was all dark in the tunnel and suddenly it was all white. This was the first time he had a seizure, and he promptly told his mother about his experience. His mother did not believe him and thought he was joking (as kids will do). However, when it happened again, his mother started to worry and sought medical assistance.

Since then he has been living with the ups and downs of medical treatment. In all the medical trails and errors, there was one medicine which particularly bothered him, a medication that could potentially make him gain a lot of weight. This led to many restrictions, such as weighing the fat, the sugar, etc. before every meal…this made him lose his appetite, in the end. But the more difficult thing for him was that in junior high school he could not eat with his friends because of it. During this time, his life was strictly regulated by the medication that he needed to take (24 pills, morning, noon, and night) and managing the portions of food, as well as food he could or could not eat because of this medication.

Thankfully he had friends during that time …but there was one that frankly annoyed him, one that overtly called him names and talked behind his back. One time this boy was talking about an upcoming trip to a group of friends. They brought up Christophe, and he didn't realize that Christophe was behind them, listening, and he said a lot of mean things about him. When his "friend" realized, instead of apologizing, he said instead, "anyway, you're going to fall, so we won't take you with us." Instead of defending him, his other friends left. Christophe says that they were scared of standing up to the bully, as he was the leader of their group of friends. He admits that none of these persons were really his friends, come to think of it.

He follows this story with his medical story, saying that he saw several neurologists during this time which only made things worse…afterward he saw psychologists and psychiatrists, and even if they tried their best, they did not succeed. This led to such a difficult time that he only had one wish, which was to stay at home. It was chaos. During this time, he lived very badly, but there were people to comfort him. There were also people who decided to stand up to the bully, including girls in his class and teacher, which made him feel better.

I told him that there was a lot of progress to be made so that people could understand epilepsy better. He agreed and said that there are plenty of epileptics in society, including famous people like Van Gogh, and most people did not even realize it. While he seemed proud of these famous people, he also told me the reverse side of the case, by saying in that in history, they tried to kill epileptics because they thought that they were witches.

This reminds him of his ongoing social problems. He tells me that people are still horrid to him, especially about his weight. He can do nothing about his weight problems, which are likely due to his epilepsy or his medication. He does not understand why, in eating quite healthy and with significant portions, he cannot manage to gain weight. He says perhaps it's the (below average) food in the hospital service, but he is not sure.

Other than the food in the hospital service, he otherwise has few complaints about living at the Teppe, because he is able to pursue activities which are interesting to him. He is clear about his project at the Teppe. He tells me that he wants to work outside, not in front of a computer, as it would be impossible for him to stay enclosed in a small space. That's the reason that he's looking for a place where he can work outside, and that's where he found out that he could work in the wood workshop. He says that after completing his personalized project, he will move to a FAM at the Teppe and continue working in the workshop. This is less demanding than working in an ESAT, in particular because he needs

a break between 12 and 2 to rest because of his epilepsy. He is ok with this solution, as it will also give him more free time to do other things.

He says he's lucky to have a private room in the service, because with the other patients, it's not always easy and he tries to avoid those with whom he doesn't get along. There are patients in the service who are always trying to cause conflict, and he does his best to avoid them, including getting involved in love stories in the service, which just cause too much trouble. For Christophe, life in the service is not always easy. In another service, he smashed his fist in the wall because a patient prevented him from sleeping. He says that he doesn't understand why he let himself get so carried away in those situations. In daily life in the service, though, he says that one needs to take each person as they are, that "we cannot change a person like we change a shirt."

Sleep is very important for him, because without adequate sleep, he may have more seizures. He has adapted his life projects to take into account this need; in turn, his lack of autonomy in the service is difficult for him, as one social educator keeps interrupting his rest time and waking him up to go to the workshop, even though he bought himself an alarm clock to be able to wake up on his own. He is frustrated that, despite telling the social educator several times about this problem, they still do not listen. He says that in the FAM, although he was still be surrounded by the doctor, he will be more free.

As he had not talked about the doctor after more than 30 minutes of the interview, I thought it necessary to ask him directly. He said that he saw the Doctor X only once so far. He was very worried however, because his first impressions of the doctor were not good. The doctor said something about the patient which hurt him. While with the previous doctor, he could discuss anything, with this new doctor, he could not discuss freely, especially in the first interview, which was very important to learn about Christophe and his epilepsy…he felt blocked. He hoped that the next interviews would go better. The problem for him was that as the doctor was attached to the service, he didn't think he had the right to change. He says that it's more possible to change one's social educator. He has a good relationship with his social educator and appreciates him because he gives him confidence in himself: his speech is calm and he believes in him.

I asked him what it meant for him to be empowered. He says that he has helped other patients, especially in relationship to new, experimental techniques. For the VNS, he was among the first patients in France to have it, and when they put it to "on" he said to himself, he thought in his head, that he had advanced for himself, but especially for the other patients. He says that he is stimulated (by the stimulator) but that such experimental treatments also advance the future of epilepsy, especially for doctors. When I insisted that the VNS also helped him, he told me yes, it helped himself, but it helped others, firstly.

Unfortunately the interview was not able to continue on this interesting point, as he started to have a seizure. Thankfully the social educator and the nurse were on the floor to help get the patient into safety. Another patient brought a pillow to help the patient. "The interview is over!" the nurse said to me laughing and helped him to his room. The seizure had lasted over 3 minutes, a sign that it was fairly serious. I wondered if this meant that he was again having serious seizures (despite the medical device which seemed to be working), or indeed whether this was indeed a "less serious" seizure for him thanks to the device. In any case, it was clear that the non-stabilization of his seizures meant considerable risk and difficulties in working.

Patient 2 - Melanie: *this interview took place immediately after Christophe's interview. Like Christophe, Melanie had also volunteered for the interview. This patient is bubbly, bright, and laughs many times during the interview. She remembers me after the interviews and always says hello when I am at the Teppe.*

When I ask Melanie to tell me about her epilepsy, she says that it started when she was a toddler due to an emotional shock, but that she does not really want to tell me about this emotional shock, which is quite personal. Since she has been at the Teppe, things are going quite well, and it's even nice, as she has found herself a boyfriend. It seems things are fairly serious between them, which helps her live well in the service despite the many inconveniences.

Like Christophe, Melanie has also been in and out of various epilepsy centers since she was eleven years old. Some centers were good; others were more difficult. Here at the Teppe she is working on her personalized project, which will consist either in a new training or to move toward work in an ESAT. She will see in function of what she can do, but she thinks that she will work in administration. It was not her first choice, when she was younger, but she says that it will fit her quite well. Other than work, she has other passions: she loves horse-riding, sports, writing, etc. Unfortunately for the moment, she may have to stop the sports activities as the doctors have detected an abnormal heart rhythm and say that she needs further tests. It's quite hard for her to be inactive. She says that she needs to be dynamic and she is worried as sports help her keep her energy. There are some histories of heart problems in her family, so she is being careful. There is, however, no epilepsy in her family.

Her epilepsy is better now than it was. Before she had huge seizures, but she says that now she knows that there are two factors, the fact that there is the disease and the fact of whether or not she is doing ok in her head. Now rather than having seizures, she has panic attacks, which are also scary. However, they are different from her seizures, as her seizures are painful. They are terrible: they feel like being rolled over by a steamroller.

It's difficult for Melanie to talk about her seizures, and she always phrases any discussion by saying that they are better now. The last time she had a seizure was when she was at her parents' house, not at the Teppe. She laughs, telling me that she is very diversified in seizures and that she really interests doctors. She says it's for that reason that she has the impression to be a guinea pig. She's a medical mystery; they never know what to give her as a treatment, so they say we will try that! Let's cross our fingers!

However, as she knows her epilepsy and her medication well, she does have a say in treatment decisions. She knows for instance that she intolerant to certain medications, so the doctors listen to her. For example, recently they asked her if she was willing to reduce one of her medications to either the morning or in the evening. She agreed, but said that they had to make sure not to put all of it in the evening, as it would not be easy for her in terms of planning her day.

For her, being empowered meant been being able to react to these propositions and having a final say in the treatment decision. However, usually she doesn't make this decision alone, and sometimes she even prefers to have her parents decide. As her mother is a nurse, she also can give useful information to the doctor. Her mother is also her advocate: when she was young, for instance, the pediatrician did not believe the patient or the family when

they told him she had epilepsy. They had to take her a video of her having a seizure for the doctor to believe her and diagnose her epilepsy officially.

That first doctor does not resemble at all the doctors she has at the Teppe. She describes her doctor as "wonderful" especially because they do not judge her. While she has had a hard time accepting her epilepsy, the thing that she still does not accept is that people do not accept her as she is…it's too difficult sometimes, especially with her family, because there are people in her family who are scared of her disease. They have seen her in a seizure and felt helpless. Her parents, her sisters and brothers have explained to them about epilepsy so that they will be less scared. One side of the family has accepted it, but on another side they are still scared and that's the reason that they see that side of the family less often. They still haven't accepted her disease; well, maybe they have accepted it, but they are still scared. They say that they will not know what to do if something happens. She says that she does not care, and she has accepted that some people will avoid her because of her epilepsy. She is ok with herself as she is, so she doesn't pay attention to other people's remarks about her. She prefers to pay attention to those people who love her and give her their attention, such as her mother, father, sisters and brothers.

She's not sure if she will "tell" her epilepsy to her employer. While by nature she is frank and tells the truth even if it doesn't please others, as for employment, she is on the fence of whether or not she will need to tell them…

However she does believe it is necessary to make others aware of epilepsy in society, so that they can help persons with epilepsy during a seizure. When she was younger, she went on a school trip and had a seizure. Luckily her mother accompanied the teachers on the trip; however, the mother was not yet there when she had the seizure. Not knowing what to do, the teacher put a sack on her head …during this time, Melanie heard everything but could do nothing! Her mother arrived and took the sack right off her head. Both her mother and Melanie herself were furious with the teacher, who could have killed her. So she thinks it's very important for everyone to learn the basics, especially in hospitals and medical-social centers like the Teppe. Having grown up among persons with the disease like her, she knows what to do, how to put them in safety. For those who don't know about epilepsy, people usually think it's better to just let the person as they are, to give them the time to recover on their own. It's not necessarily the thing to do, according to Melanie. The first time that she saw the social educators in another center deal with a seizure, she was scared for the person. She had already seen one of her friends die due to a seizure. It's for that reason that Melanie has learned first aid to help other patients. She says that epilepsy is not without consequences, as one can die from a seizure. It really matters in these situations to put the person in safety; it can mean life or death to the person.

One time was particularly scary for her parents, as during a seizure she stopped breathing. They decided to call an ambulance; however, she arrived at the hospital completely disorientated and without her parents. She didn't know here she was, she was completely outside herself…she kept going in and out of the hallway, and in her room...she kept wondering where she was, where were her parents, where was her house, etc. She was completely lost. And during this time none of the hospital staff came to see what was happening. She could have had seizure after seizure and no one would known. She was petrified. She had missed the moment of the transfer from her house to the hospital, just she had missed many other moments of her life. These missing moments of life with

epilepsy are difficult to live with…but she says, she is as she is and she manages as best as she can.

She can generally tell when her seizures are about to come, about two minutes in advance. This gives her the time to tap someone on the shoulder and get assistance. Melanie says that she does not joke about epilepsy, especially considering that the person next to her will not necessarily know what to do. For her it is very important to do everything to help herself and to help others…well epilepsy remains a very sensitive topic for her, but she does manage…

Patient 3 - Michel*: I had already met this patient several times before in the writing workshop proposed at the Teppe. As we were knew each other already, the interview was quite easy and flowed naturally. He even left his morning art workshop to talk to me. Unfortunately, I had also seen this patient have seizures in the service. While working at the bar in the evening for patients, he fell like a doorway straight down on his head; luckily, a patient was nearby to catch him, so he did not hurt himself. He recovered quite soon afterward and was able to continue his evening socializing with other patients.*

Michel says that when he first came to the Teppe, about six years ago, he was in a different service. However, during that time, he was really annoyed by all of the seizures he was having, so it made it difficult to complete his personalized project. However, little by little, he understood that the disease was "in him" and that he needed to "learn it." Then he became much less angry about his seizures.

He has had a long healthcare journey, with lots of different treatments, but his epilepsy remains refractory. He has had epilepsy since he was 13, due to an emotional shock of the death of his grandmother. All the medication has done is to change his seizures…sometimes they work for a while, and then when his body adjusts to the medication, it is necessary to change them again. Like the other patients, he has been in and out of various centers since his adolescence. It's difficult to remember how much time he spent in various centers, but he does recall that it was the social worker at his second center who recommended that he try the Teppe.

He has a hard time describing his seizures, but says at the beginning that they were mainly absences and that he had a lot of those (around 80 per month). Now he has more violent seizures, tonic-clonic seizures, with auras, and most of the time he falls behind (on his head). He refuses to wear a helmet, however, like some other people in the service. Luckily he is able to recover fairly quickly after these seizures, thanks to the VNS. He says that it depends on each individual person; for him, although the VNS does not stop the seizure, it does help him to come back after the seizure. Unfortunately the VNS seems the only solution for the patient, as he has two epileptic regions in the brain, which make him ineligible for surgery.

As for his relationship with his doctors, sometimes he gets very frustrated. He says that sometimes it's necessary to insist on his right to participation in the treatment plan. He says that, *"we are patients here, we are the sick ones, so it's not for them to do everything…patients also have rights. It's not doctors that know everything."* Sometimes, the doctors do not agree with him, even after he says that he does not want to try a certain treatment. Sometimes he says, "*I really have to insist, as they do not always listen to me. They still try to give me the treatment they want to give me, that's why sometimes we don't really have the choice, and we have to be really strong and insist that we have the right to decide."*

His seizures are related to his treatment, but also to his lifestyle. Before coming to the service, he was working at the ESAT and was having between 8-16 seizures per month; now that he has returned to the hospital service, it is more in the range of 6. This is because working at the ESAT caused him considerable fatigue. Finally he had to give up working because of this. It is a pity for him: he did a job he enjoyed. His new personalized project will help him integrate a FAM, as it doesn't seem possible for him to work. He is seeing if it will be possible to integrate a FAM to be closer to his family, as the Teppe is at the

opposite end of France from where he grew up. As it's not possible for him to work, he is now investing in other projects, such as writing and sports.

For him, being empowered is related to his treatment, but also to his life. It's not just a matter of participating with the doctor in the treatment plan, but also exercising his rights in the service. For instance, sometimes rules change from social educator to social educator. One says that they have the right to do something; the next day another person will say that they have no right…and sometimes he says that the patients have to deal with the healthcare provider's emotions. When they get angry, he tries to stay calm and reason with them. If he didn't have this right to talk openly to healthcare providers, he says he would leave this place, immediately.

For him, other than these small hiccups, life in the service is fairly good. The only real problem for him is his lack of autonomy in relation to taking his medication. In another service (the ESAT), he was allowed to be more autonomous and to take all the medication he needed for the week in his room…now in this hospital service, they cannot let the patients take their medication autonomously without prior verification. Also in the ESAT, he could do his laundry independently, while here someone does it for him. Also he cannot take a shower when he wants: it is regulated to the common times for taking a shower in the service (to make sure there is someone on hand in case the patient has a seizure while in the shower).

Despite these changes, in general he likes being at the Teppe, especially because he has made friends in the service. He also tries to see his parents as much as possible during his holidays. At first it was difficult with his mother, because she had trouble accepting his epilepsy. She was always around him, hovering, to make sure he was safety. Finally he got tired of this and told her to back away. Being at the Teppe helps, as he can have some independence from his parents.

Patient 4 - Thomas: *Thomas was selected by the social educators to do an interview with me, given his progress in his personalized project as well as his successful management of life in the hospital service and in his private life.*

Thomas has been in the hospital service for five years. At one point, he left for three months to try a training in administration, but he failed and returned to the service. Now he is trying to do an internship to prepare for work in an ESAT. His personalized project is geared to help himself him toward that goal. He says that he is very motivated for work, but that it is challenging for him to get up in the morning (due to his medication); however, otherwise there is no problem for him. At the Teppe, he first tried do another type of work outside, but it was difficult due to other health problems. Now he is in subcontracting and it pleases him.

As for the personalized project, he is involved but not always the main actor. It is the social educators who decide how the project has evolved. If he is not in agreement, however, his opinion can be taken into consideration in the next report. He feels like he is empowered however in his project as he decides what kind of work he would like to do. He is also able to discuss freely with his doctor. As he says, *"we speak the two of us. We speak together before making a decision."* For example, he wished to take away a medicine that he believed he longer needed and was making him overly tired. The doctor and he agreed that they would try to eliminate the medication after he completed his internship; they have now taken it away. Taking away this medication makes a big difference in his life, as he is less tired and can do more in his free time.

For Thomas, being empowered means that it is for him to decide his life; that is up to him to make his own choices. For him, the role of the doctor is to decide the treatment plan and ask him what he thinks…however, it is not the doctor who helps him toward his life objectives…that is more the role of the social educators. The social educator meets up with him every week to talk about everything in his life, such as money and being able to get up in the morning, how his internship is going, etc. The social educator gives him advice so that they can work out together how to make the personalized project be successful. He says it's not only the social workers' training that allows this needed assistance to "climb the stairs", but also their personal relationship, which is rewarding to both of them.

Thomas has had severe epilepsy since the death of his grandmother. He says that he while he has been epileptic since birth, it was with the death of his grandmother that it was diagnosed. Before they usually presented themselves as absences and his mother didn't understand what was happening, so they didn't diagnose his epilepsy right away. It was only at 16 with the death of his grandmother that he started to have tonic-clonic seizures, so it was easier to diagnose. The first time he had a seizure was at school and after his diagnosis, he often had to go to the nurse's office to take breaks after having a seizure. His seizures started to change when he got older, but he was still able to pass his *brevet* (junior high school exam); however, even so he decided to go to high school in a center specialized in epilepsy, and when he was 18, he came to the Teppe.

Thomas' epilepsy is now stabilized, giving him considerably more freedom in the service compared to other patients. An important factor in his stabilization was one in which could manage his behavior, as he can become violent without this medication. This medication manages to "control him." Because he can now control his behavior, he is a leader in the service. He gets along with all of the social educators and patients and brings the "good

vibes." He relates to me the last time he was gone for dinner. When he came back, another patient told him that there had been a bad atmosphere at the table; when Thomas returned however, he turned around the collective mood at the table and everyone was happy. He says that there is even one patient who always makes sure to sit next to him. Another patient cried when she learned he would change the service. He says everyone treats him like their older brother. While he's happy that they look up to him, he says that he needs to think about planning his life and will need to leave the service someday.

Thomas gets along well with his family and is the only epileptic in his family. His father however was a source of tension for him in his adolescence, as he abandoned the family when he was just one year old. When this father returned and learned about his epilepsy, he told the judge that Thomas was not "his son." The judge was so scandalized by this assertion that he had him repeat this statement several times to make sure he understood. However, his other family relationships are generally good. If his mother was really scared at the beginning of his epilepsy, and used to call the ambulance every time he had a seizure, now she has accepted it. Also they are happy that his epilepsy is now stabilized, as it makes them worry less about him. Still, as he says, he will be epileptic all of his life, as all of his brain is affected.

Thomas is in a serious relationship with another patient who lives at the Teppe. As she is still on site, he can see her everyday. However, his girlfriend is not stabilized and falls when she has a seizure. He is scared for her and so he is always around her, holding her hand, or taking her around the waist to "catch" her in case she has a seizure. He prefers to do that to make sure she is safe, and says that this does not bother her. Thankfully his seizures are stabilized, as it would be quite difficult for her to help him (he's quite tall!) and when he has seizures, he falls "stiff as a stake."

Thomas has seen what happens when he doesn't take his AEDs. He says there was one time three years ago (his last seizure) when he forgot to take his medication when he was doing an internship. He also had a lot of stress at his internship, as his boss always wanted him to work faster. It was a stressful time for him. When he went back home, he had a seizure because he forgot to take his morning pill. He had been so late to work that it slipped his mind. He insists on the fact that he forgot to take his medication that day, because otherwise his epilepsy would have been considered stabilized.

In addition to taking his medication, he is doing his best to learn to be as autonomous as possible, as he knows that he cannot live with his mother or at the Teppe forever. He says that he wants to "fly with his own wings." He has a lot of autonomy compared to other patients (such as having the liberty to take a shower when he wants), being in Autonomy 2 in relation to taking his medication, etc.

He emphasizes that it is important for him to invest his time wisely at the Teppe, to make sure he is ready for the ESAT, because if he returns to his house and he is not ready, his project will surely fail. He prefers to wait and see if he really has the level needed to work. Given his past failures, he knows that he needs to take time to understand the feasibility of his personalized project, and luckily, he can take the time he needs at the Teppe.

Patient 5 - Colette: *this 22-year old woman wears a helmet due to the severity of her seizures. I have seen in her various times at the service, such as at meal times and in the evening at the bar in the service; however this is the first time that I have had a chance to speak to her directly.*

Colette says that she "received" her epilepsy when she was five years old. It was her mother who spotted something wrong, because she witnessed some inexplicable, some kind of "bizarre" movements when she was a baby. However it was only at the age of five and when she started to fall down during seizures that it was possible to diagnose her epilepsy.

Colette has difficulty remembering her seizures, because they usually happen at night and she knows she has had a seizure when she wakes up with a tongue bitten. It is for this reason that she has a camera keeping track of her seizures at night in case she needs assistance.

These temporalities make it strange that she wears as helmet during the day (if her seizures are only at night?). However, she says that in September and in October in the last year, she had several severe seizures in the daytime and fell. She doesn't want it to start again, because the first time, her head was opened from the fall…so the nurses and her parents thought it better to give her the helmet to wear even during the daytime.

While she likes being at the Teppe, she misses her parents terribly. It's a bit tricky to arrange her holidays at the Teppe, as her parents are divorced. In particular, she gets along better with her father than with her mother. Her father is more protective of her, as he understands that she has some limitations (in particular cognitive difficulties), but her mother says that she needs to be the same like other children. This puts a lot of pressure on Colette and she says she prefers her father over her mother. She even says that she loves her father more than her mother, because of this. Since she's been at the Teppe, she is seeing a psychiatrist, who has helped her with her anxiety about not seeing her parents and the problems with her mother.

She is at the Teppe because she wants to be like other young adults, to have her own apartment and find what she likes doing. She thinks that she will stay at the Teppe (in a FAM) and that she will continue in the florist workshop. She is learning to be more autonomous, little by little. Although she is looking to find her way in life, for the moment she is not really making long-term plans. Although her epilepsy is more or less stabilized, she had those big seizures in September, so she is worried where this might go and how this might impact her plans.

As for being empowered, she does not really wish to take an active role in her relationship with the doctor, and prefers for him and for her parents to decide. Because she is not empowered in the relationship, and because of her cognitive difficulties, she often does not understand the medical acts prescribed for her. For instance, she doesn't understand why they keep her VNS. Especially as she doesn't remember her seizures, and they take place at night, it is hard for her to testify if they have increased or decreased and she does not really understand their utility. Because of this, usually the healthcare team takes care to note her seizures and report on this back to the doctor. She also describes in a passive way the medical acts taken by doctors, such as they "took" an EEG, they "took" from me some exams, etc. While this patient may have troubles understanding information, it does seem

that sometimes her parents “take her place.” While she prefers this situation, she does feel left out of the treatment plan and is missing information about her epilepsy.

In daily life in the service, she is also relatively unempowered. Despite insisting that she doesn’t want to do sports for example, the social educator “forces” her. Colette sometimes just wishes she could be left alone. Despite her difficulties, she is appreciated by other patients in the service and tries to help them when they have seizures (she was the one who helped Thomas when he fell in the evening).

5 Narratives Cases of Patients at Huashan Hospital (Shanghai, China)

Patient 1 - Mei Ling: *this was my first interview in Shanghai, with a 35-year old woman who came with her mother to be interviewed. Because of the weight of her disease on her workplace and her family relationships, this patient's story stayed with me throughout my research project, and I thought it fitting to highlight her story in Chapter 2, when talking about difficulties in the workplace, because even though Mei Ling is able to keep a job, she is not flourishing in this job because she is not fully integrated into the workplace by her colleagues.*

This patient is haunted by her epilepsy. When asked to tell about her epilepsy, she says right away that she cannot tell her epilepsy to her colleagues. Society's weight and the bad impression that it has (as the goat's disease) make her hide her epilepsy and make it difficult to function normally. She suffers from depression and she takes it out on her family by being aggressive when she cannot do so at work. Her colleagues think she is privileged as she often leaves early, or misses work for her doctor's appointments. They don't know she has epilepsy, but they think it's unfair that she gets special privileges such as extra holidays to go to the doctor's office. The impact on the family is immense: they worry about her future without them, they worry about her inability to find a partner to support her, they worry about her depression. They worry more about these factors than they worry about her epilepsy, which seems comparatively minor (only occurring in certain temporalities and the duration is short). The side effects of the medication, however, seem to be much worse than her epilepsy: her inability to concentrate when she started taking one anti-epileptic caused her to quit the job she enjoyed; she now suffers from depression whereas before she was a bright and positive woman. Everything crisscrosses and I don't know from her narrative which is worse: to have epilepsy, to take AEDs, or to be considered a "privileged" person at work.

The one bright spot in her life seems to be the other patients, especially the patient group the "Seahorse Club" in which she participates. In the group, she is able to trade advice on treatments and doctors with other patients and families, as well as being part of the wider patient and healthcare provider discussion about epilepsy.

The weight of the disease and the side effects of the medication weigh on both her and her family. She first had a seizure when she was 16 years old. At 25, she found that she had an ache in her neck and the doctor said she had a thyroid problem. She had an operation 10 years ago for this, hoping that it would cure her epilepsy; however, since the operation, it has instead gotten much worse. She does not much trust doctors these days. She was also diagnosed with lupus last year. Now she thinks the lupus caused the epilepsy.

She says people don't respect people with epilepsy, so she hides her condition from her colleagues. She has depression. She is constantly asking herself, *"why did I get this disease?" "Why do I have epilepsy?"*

Her mother says that she is very good at school and used to be an accountant. As she was taking AEDs that interfere with her concentration, she couldn't calculate numbers anymore and had to quit to a less difficult profession. The medication has also impacted how she spends her free time. She enjoys drawing pictures and music, but now she is doing these activities a lot less and is afraid of being alone. Usually she would have come to the interview alone, but now she is afraid and doesn't feel safe to go outside by herself.

She has relatively minor seizures (absences) and it is generally at the time in which she has her period. Sometimes she loses consciousness, sometimes not. She recovers quite fast after these absences (1 minute later). She can keep doing work during this time, but as she knows that these seizures slow her down, she continues doing simple work during the recovery time. Her colleagues have never noticed that she seemed to be having a seizure. During her seizures, she sees/hears voices and seems to be falling down but does not. After taking AEDs, she still hears voices, but as an additional as a side effect, she cannot see things clearly, and has to close one eye to focus.

She quit her job as an accountant and she is now a social worker. The boss knows she has a medical problem, but her colleagues do not know it officially. However, they suspect that there is something wrong. One of her colleagues has even stopped talking to her (they treat her like she is "dead"), but not because of her epilepsy. They know that she has some kind of serious health problem, and that boss will give her holidays, so she is viewed as "special." The boss is kind, he gives her time to go to doctor's appointments. Her boss does not know that she has epilepsy because she believes if they find out, she will have to quit her job. She now keeps her distance from her friends as well, due to this exclusion in the workplace, even though they did not reject her because of her disease.

She says epilepsy has a bad connotation in Chinese (goat's disease) so cannot tell anyone about it. She knows many patients through the patient group at the hospital and through the WeChat group. The WeChat group was spontaneous, but the hospital heard about it and decided to support it. They now provide social activities and information about epilepsy. They advocate that in China, epilepsy needs to change its name (it has already happened in Hong Kong). They are trying to pass the message that people with epilepsy act normally when they don't have seizures. They are also tried to raise awareness on the economic and mental burden for the family and for the patient. The epilepsy patient group is trying to empower patients to have a positive attitude to the disease, but Mei Ling thinks they should focus more attention on society. They should work to decrease discrimination and changing the name of epilepsy is one of the first things they can do.

Her mother highlights the fact that the medicine she is currently taking has caused a significant personality change in her daughter, namely depression, which affects the whole family (a "boomerang effect"). She used to be very good tempered, but now says hurtful things to her mother such as, *"if didn't exist in the world, I wouldn't have the disease."* She is their only child and they are worried what it will be like for her when they are gone. The mother highlights the fact that their daughter loses her temper at home, instead of at the office and makes the parents suffer in return. Her mother hopes she will learn to control her temper. Her mother feels a lot of pressure and cannot tell others. Although at the beginning of the interview, she said that the main effect of the epilepsy was on her daughter, everytime she intervenes in the discussion she talks about the effect of her daughter's depression on the family as a whole.

Patient 2 - Biyu: *Biyu is a 50 year-old woman who has finally been able to stabilize her epilepsy with the help of AEDs. The first thing she talked to me about was the visible signs of epilepsy that continued to bother her (namely a scar on her lip). In Biyu's story, the social and economic burden of epilepsy seemed to weigh more heavily on her than the disease herself.*

Biyu has had refractory epilepsy in the past, and like many patients, she went to several specialists and tried several different treatments, including TCM (Traditional Chinese Medicine). However, she is now quite loyal to the hospital and to the neurologist she sees at the hospital. This seems to be principally because of good doctor-patient communication. She trusts her neurologist and knows that she will recommend new drugs if there is a better combination available to her. Another way in which she showed trust in her doctor is when reflecting about the advice she receives from other patients: rather than going to a new doctor when hearing about a new drug, she recognizes that different patients try different medicines and what is good for them may not be good for her. She says she will only take their advice after consultation with her doctor.

This patient realizes that her epilepsy is individual and what may be good for her may not be good for the next patient. The doctor also treats her as an individual and her disease as individual. The side effects of Biyu's medication continue to cause some difficulties in her daily life (such as cooking). In general however she is able to live with the medication with few side effects. Fewer side effects were also an important factor for her in staying with the same neurologist. While she tried some other doctors, the medication's side effects she experienced were quite important (excessive fatigue) which decreased her trust in the other doctors. As this hospital was able to choose a posology that had minimal side effects, and this seems to be a factor in her trust of this hospital service.

Both self-imposed and felt stigmas are present in this interview. While society does not actively stigmatize her (i.e. her neighbors help her when she has had seizures in the past), they discriminate against her when it comes to employment (they refused to hire her in her neighborhood when she looked for work). Still, she seems to be "coming out of her shell" now that she no longer has "dangerous" seizures and communication with other patients through the patient group is one of the reasons she has been able to move forward beyond her fear.

The economic burden of epilepsy is quite important for this patient: while the disease itself does not limit her, she is unable to do further studies, learn new hobbies, or travel due to the fact that she is unable to afford these activities. In both Mei Ling's and Biyu's stories, the social and economic impact of epilepsy felt through employment significantly impact their ability to live well.

One of the main benefits of joining the hospital's patient group is reducing the fear she feels about epilepsy (thus encouraging her to talk more about the disease). She says for instance that if she now goes travelling with an agency, she would now tell the group leader about her epilepsy. This is thanks to the patient group that has helped her to "feel normal" with epilepsy.

Patient 3 - Qi: *Qi is a 38-year old woman whose story is fragmented due to memory and confusion relating to her epilepsy and other factors arising around the start of her epilepsy (a coma in which she lost significant memory when she was 19).*

She tells me the story of a troubling problem in communication with her doctor, who did not tell her diagnosis of epilepsy when it was discovered by the medical team following a coma. He referred to it as, "you have a problem in the brain." The doctor however assured her that it would get better. It did not. She learned about her epilepsy for the first time when she was 28 at Huashan Hospital, nine years later. During this time, she had been taking AEDs without realizing that they were for her epilepsy.

Since 2008 she has been on a stable drug regime. She says she has no side effects from the present drug regimen, that the treatment seems suitable for her. Since she did not have a diagnosis for many years, she cannot recall exactly the evolution of her epilepsy: however she thinks that at first she had seizures in which she lost consciousness or had some kind of "aura" helping her to see that a seizure was coming, but that now the severity of the seizures has decreased (most likely due to the AEDs).

Financially she is dependent on her parents as she is not working, and emotionally the diagnosis is difficult for the family as they blame themselves (they were not present at the time when she went into the coma). She was working at her father's company, but the factory closed down and since then she has been unable to find a job. She is quite open about her epilepsy at the interview (she believes it is her duty to tell) but unfortunately this has had negative consequences for her in getting an offer of employment. Her family, although of retirement age, are still working in order to support her, which cause significant family problems. At 67, her father is still looking for a job in Shanghai to look after her so that they can afford her medication.

The fear of passing down her epilepsy or of not being able to take care of her child has prevented Qi from considering having a child, although her epilepsy seems pretty stabilized now. Self-induced stigma seems to be a factor preventing her from developing other capabilities, because she feels she cannot live normally due to the disease. For example, when she goes on an activity with her classmates from primary school, she feels uncomfortable as they do not share the same life trajectories (i.e. they all have children and talk about them). Now she tends not to go to these meetings.

While her doctor did not forbid her to have kids, she stops herself due to fear of passing on the condition. However she has experiential knowledge that helps her live well with her condition: she engages in hobbies such as writing, painting, or drawing which help her to relax and make her happy and she says, also help to reduce her seizures.

Patient 4 – Li: *Li is 68 year old woman that is willingly passive in her treatment and in general knowledge about epilepsy, preferring to regulate this role to her doctor. A student doctor asked if she would be willing to talk to me after seeing her in the clinic. This was the only patient I interviewed who did not take part in the hospital's Seahorse Club.*

Li's husband, when he was alive, did not help her to know her epilepsy, as he did not tell her what happened during her seizures. In addition, Li does not use Wechat or other patient networks such as the Seahorse club, and does not know other people with epilepsy, and therefore she does not have information on epilepsy from other patients. However, she does have some experiential knowledge of her epilepsy. She know seizures by absences, i.e. she knows when seizures have occurred when she comes back and sees that she now longer has vegetables in her hand, or that she has burned her hand. She has also identified emotional events (such as the death of her husband) with the frequency of her seizures. However she does not do anything specific to get to know the trigger factors or her epilepsy or how to better control them. In general her relationship with the doctor is a purely service relationship: she comes to the doctor to renew her prescription. As she repeated a great deal during the interview that she was tired, this is likely either due to her AEDs and/or her epilepsy that could be affecting her ability to be more active. It could also be a sign that her seizures are more frequent then she realizes.

She was diagnosed with epilepsy quite late (around 50 years old), so epilepsy has in general not affected her family or work life; however, the impact of seizures do seem to affect her daily activities. When she had a particularly difficult seizure in public last year, her son insisted that she now always stay at home and found her some outside assistance with daily tasks such as shopping. As she is alone, she cannot tell her doctor when and what happens during her seizures, which may affect the ability of the doctor to find the right treatment plan. It has also led to her social isolation, as her son is very busy and cannot see her much. The visible signs of epilepsy (such as scarring due to having seizures during cooking) are important to her (when asked about epilepsy she talks and shows these "visible signs"). These visible signs and her son's worry (overprotection) seem to have more impact on her then her actual seizures, which she says do not make her sad or anxious.

Although she was not told so by the doctor, she thinks maybe overtiredness led to epilepsy, as she went to work from a very young age and had to take care of her sick sister in the hospital.

She doesn't know anyone else with epilepsy. She has no family history of epilepsy, and no relatives have epilepsy either. She doesn't learn about epilepsy, and she doesn't want to learn about it.

Patient 5 – Chen: *has lived through trials and tribulations with AEDs and has suffered social and economic stigma due to his disease. He however, has become a leader for other patients, with and without epilepsy, at the hospital.*

Chen is a 60 year old patient who has had a frustrating experience with AEDs. Since his teens, when first diagnosed, he has not been able to find anything which stabilized his epilepsy until recently, when he started a new clinical trial. This medication has now reduced his seizures significantly. Although this new medication has some side effects (such as drowsiness), it does not stop him from doing the things he enjoys (such as cooking, travelling, drawing, taking photos, etc.) so he is happy about this new medication. Unfortunately however, this clinical trial is coming to an end, and Chen is not sure he will be able to continue taking it.

He says that he is one of the few in the Seahorse Club that has been able to work due to his epilepsy. After graduation he went to work in a factory and after that he was a teacher in primary school. He has been able to work and have a fulfilling career as a teacher; however he was finally "forced" into an early retirement when the president of the school found out about his epilepsy.

This had an economic impact on him, but also an emotional impact, as he really enjoyed his job and relationship with the kids. He loved the kids, but he says that he had to stay positive and face reality. He has accepted this situation and now he devotes his time to helping other epilepsy patients in the hospital's club. He also volunteers at the hospital, helping other types of patients navigate the complex and stressful hospital process.

Although he has accepted the constraints that epilepsy has brought to his life, and has used that to move in directions which help others, he still feels the burden of his long-term disease and hopes someday for a cure. He feels that his body does not belong to him. He maintains, however, that life is unfair to everyone in some way and that is why he is willing to help other patients.

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Le patient acteur de sa vie :
vers une approche collaborative avec le patient

Ce document est écrit à l'intention des patients, de leur famille et du personnel soignant

Introduction

Une famille a un enfant, Nicolas, qui est actif et créatif. Un jour, quand il a 4 ans, Nicolas semble avoir un AVC (un accident vasculaire cérébral). Un côté de son corps est complètement immobilisé. Les parents ne savent pas quoi faire. Trente secondes plus tard, l'AVC s'arrête et Nicolas recommence à jouer.

Quelques jours plus tard, les effets de l'AVC supposé se répètent. Les parents appellent leur médecin traitant qui envoie leur fils aux urgences. Le technicien fait un EEG (la machine responsable du diagnostic de l'épilepsie) et annonce un rare type d'épilepsie. Le neurologue n'aucun doute quant à l'interprétation du diagnostic posé par le technicien et donne au patient de très fortes doses d'antiépileptiques. Le patient devient très passif. Les parents ne le reconnaissent plus. Nicolas ne joue plus. Il ne sourit plus. En plus, les crises d'épilepsie continuent. Les parents réagissent immédiatement, frappé de peur. Ils vont consulter le neurologue plusieurs fois. Ce qu'ils remarquent, c'est qu'il ne les regarde pas dans les yeux. Il est évasif et refuse de négocier le diagnostic ou le traitement.

N'ayant pas confiance dans ce médecin, tout en voyant l'état de leur fils empirer, ils décident de recourir à une autre expertise. La relation avec le médecin dans ce nouvel établissement est très différente. Immédiatement, le neurologue communique l'incertitude du diagnostic. Le patient paraît correspondre à un type d'épilepsie avec une certitude à 68% alors que le seuil minimum à atteindre pour le diagnostic est de 70%. Le neurologue qui, à nouveau, n'a pas pu aider son patient, dit à la famille son hésitation à poser ce diagnostic.

Au lieu de maintenir le protocole proposé, le neurologue consulte d'autres spécialistes et transmet à la famille les conclusions de ces échanges. Tout au long de ces démarches, le neurologue communique son incertitude, puisque l'enfant ne correspond pas exactement à

un diagnostic particulier. Le traitement nécessite d'être planifié avec soin par le médecin, la famille et le patient. Le médecin a besoin non seulement du consentement de l'enfant et de la famille, mais aussi de leur collaboration pendant cette période difficile.

Finalement, le traitement s'est avéré être, comme dans beaucoup de cas, une méthode d'essai-erreur de différentes posologies. La famille, le patient, et le médecin ont travaillé ensemble vers de nouvelles solutions. Au lieu d'essayer d'arrêter complètement les crises, ils ont essayé des posologies moins lourdes, qui ne les empêchaient pas totalement les crises mais qui permettaient à l'enfant de continuer à être actif et créatif.

Pour le médecin, la possibilité de parler avec ses confrères mais aussi avec la famille et le patient autour de cette incertitude du traitement a ouvert un espace de confiance entre le médecin, le patient et sa famille. La famille sachant enfin que son fils était entre de « bonnes mains » a pu enfin se détendre et voir se dissiper sa peur.

Le temps nécessaire pour trouver le bon traitement a été de trois ans. L'enfant a grandi : il a maintenant 7 ans. Le neurologue proposait tout au long du processus que le patient vienne avec ses parents en consultation malgré son jeune âge. Après trois ans, et une dose moins lourde d'antiépileptiques, le patient connaît très bien son épilepsie et son traitement. À partir de ce moment, les parents décident de laisser leur enfant voir son médecin sans eux. À l'école, Nicolas a fait part de son épilepsie à ses camarades pour qu'ils ne soient pas effrayés quand ils sont témoins d'une crise.

Après cette période difficile et parfois très longue, pour le patient, pour son médecin et pour la famille, Nicolas a enfin eu un résultat inespéré : la stabilisation de son épilepsie. Les crises ne viennent plus au quotidien d'une manière imprévisible détruire la vie de Nicolas et de sa famille.

Après plusieurs années de stabilisation, le neurologue décide d'arrêter les médicaments. Un jour le médecin dit à son patient, « nous ne sommes plus obligés de nous voir, mais vous pouvez revenir consulter si vous le souhaitez. » Le patient et le médecin ont eu du mal à se dire au revoir.

Pour le médecin, ce cas était un vrai exemple d'une alliance thérapeutique. Il a même eu une fin heureuse puisque le médecin a trouvé une solution pour stabiliser l'épilepsie de son patient. Pour Nicolas, cela a été également une période importante, un temps de sa vie où il a appris à connaître ses capacités et à établir des relations avec les autres. L'épilepsie a fait peur, mais a permis à Nicolas de devenir acteur.

Il est souvent dit aujourd'hui que le patient – et même le consommateur – est roi. Les associations de patients prennent un rôle croissant dans les politiques de soin. Les « patients experts » deviennent des enseignants pour de futurs médecins. Les institutions de soin favorisent une « alliance thérapeutique » où le patient et le médecin doivent travailler ensemble en vue d'un traitement adapté.

En parallèle, l'idée d'un patient « actif » est aujourd'hui mise en valeur à la fois comme un droit, mais surtout comme une responsabilité, tant pour le médecin que pour le patient. Nous demandons à la fois au médecin de faire participer le patient lors de la consultation, et au patient de connaître et d'apprendre sa maladie.

Malgré ces évolutions du système de santé, la relation médecin-patient continue de susciter de l'angoisse, pour le patient, pour sa famille et pour le soignant. Dans la véritable pratique de la consultation, nous sommes souvent loin de l'alliance thérapeutique encouragée par les institutions de soin. Créer un environnement propice à une participation de *tous* les patients à la prise de décisions concernant le traitement est aujourd'hui une priorité dans les politiques publiques. Si le concept de patient acteur reste plus une théorie idéale plus qu'une réalité, nous produirons des arguments pour établir que c'est parce que nous n'avons pas assez sollicité l'avis du patient sur la forme et le contenu de cette participation.

La recherche menée dans ce travail tendra vers une définition du patient acteur *avec* la contribution des patients : *le patient acteur de sa vie*. Notre recherche développe également le concept de « la famille actrice » afin de comprendre et valoriser la participation des familles. Nous développons notre sujet sur le terrain, dans deux pays, la France et la Chine. Nous avons travaillé avec des associations de patients et des hôpitaux spécialisés en épilepsie, avec leurs patients et avec leurs soignants.

Nous avons choisi plus précisément d'étudier notre sujet avec des patients atteints d'épilepsies pharmaco-résistantes. Cette population représente un tiers des patients qui ne peuvent pas être stabilisés avec des traitements médicamenteux. Ces participants sont peut-être le cas idéal de notre conception du patient acteur puisque les traitements actuels ont une efficacité limitée. Cela implique qu'ils soient actifs dans la prise de décisions quant au traitement et qu'ils développent des savoirs expérientiels pour mieux vivre avec leur maladie. Ou bien ils pourront apparaître comme *le cas limite* de notre concept à cause des handicaps liés à cette non-stabilisation qui affectent parfois leur capacité d'être acteur. Cependant notre choix est lié au fait que nous souhaitons que la notion de patient acteur ait du sens pour *tous* les patients, incluant ceux qui n'ont pas de « bons résultats » dans le soin. Nous choisissons donc de développer notre concept avec ces patients pour soutenir l'idée qu'ils sont tout aussi capables d'être acteurs, si nous écoutons leurs contributions.

Nous avons commencé notre parcours avec un cas de réussite, l'histoire de Nicolas. Sa situation reste un rêve pour beaucoup de personnes affectées d'épilepsies pharmaco-résistantes, qui n'arrivent pas à trouver une solution médicamenteuse pour arrêter leurs crises. Cette histoire n'est pas présentée pour donner un faux espoir quant aux potentialités de l'alliance thérapeutique aujourd'hui. En tant que société, nous acceptons de plus en plus les limites de la médecine « moderne » à nous guérir de nos maladies complexes et difficiles. Cependant, si Nicolas a trouvé un « bon » traitement pour son cas, c'est parce que lui et sa famille ont pu construire une relation de confiance avec leur médecin. Cela leur a permis aussi de collaborer avec lui dans la prise de décisions. Dans cette recherche, nous cherchons donc à comprendre comment une telle alliance peut être possible pour d'autres patients.

Notre exposé suit un cheminement qui nous permettra de comprendre les conditions de réussite de Nicolas. Nous chercherons d'abord à comprendre si les conceptions actuelles du patient acteur reflètent l'expérience vécue de patients comme Nicolas, afin de voir si les programmes développés ont un sens pour eux. Ensuite, nous examinerons la peur ressentie dans le cas de Nicolas et sa famille lors de la découverte de la maladie, leur expérience vécue en société et au sein de la consultation. Nous allons également essayer de comprendre les peurs du premier médecin. Finalement, nous chercherons à comprendre la relation construite avec le deuxième médecin, qui a permis un bon résultat pour le patient

et sa famille. Ces investigations nous permettront de proposer des approches à partir du patient, le *patient acteur de sa vie* et la *famille actrice de sa vie.*

Difficultés de traduction

En français, nous utilisons les mots « patient acteur » pour montrer un rôle grandissant pour le patient dans sa prise en charge. En anglais, l'expression le plus souvent employée est « patient empowerment. »[1] *Empowerment* suivant son étymologie présente deux dimensions, l'idée de « pouvoir » et celle d'apprentissage nécessaire pour accéder à ce pouvoir.[2] C'était au cours des années 1970, à la suite des mouvements en faveur des droits civiques, que le mot « empowerment » est devenu politique, comme nous l'expliquerons plus loin. Le mot anglais « empowerment » reste aujourd'hui la seule expression capable de restituer ces changements sociaux concernant l'acteur à la fois comme patient et comme personne en société. L'expression « patient acteur » en français est plus neutre, mais elle manque l'histoire à l'œuvre dans ses mouvements sociaux. Cependant, le mot « acteur » en français nous donne une ouverture intéressante : il nous permet de voir le patient comme un acteur aux côtés du médecin et de sa famille.

Influences sur la notion du patient acteur aujourd'hui

Il est souvent dit qu'en France, l'appel à la participation des patients dans les décisions concernant leurs traitements vient des mouvements citoyens. Nous citons souvent les crises sanitaires et le rôle politique joué par les associations de patients à partir de la crise du SIDA.[3] Nous les citons comme catalyseurs de la naissance du patient acteur en France. Alors même que cette vision met en lumière l'appel citoyen pour une démocratie sanitaire, elle reflète imparfaitement son développement sur le terrain. Elle nous éloigne notamment des premières conceptualisations « d'empowerment » qui ont eu un impact important sur notre compréhension du patient acteur. Cette approche ne prend pas non plus en compte d'autres influences, y compris celle des mouvements politiques de « New Rights » aux

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[1] Bacqué, M.-H., Biewener, C., 2013. *L'empowerment, un nouveau vocabulaire pour parler de participation ?* Idées économiques et sociales 173, p. 26.
[2] *Ibid.*, p. 25.
[3] Voir par exemple, Mougeot, F., Robelet, M., Rambaud, C., Occelli, P., Buchet-Poyau, K., Touzet, S., Michel, P., 2018. *L'émergence du patient-acteur dans la sécurité des soins en France : une revue narrative de la littérature entre sciences sociales et santé publique*. Santé Publique 30, p. 75.

États-Unis et en Angleterre, qui favorisent le patient « consommateur » en vue de réduire les coûts de soin. Cette vision ne nous permet pas non plus de mettre en évidence des mouvements pour plus de reconnaissance qui venaient des infirmiers et autres professionnels de santé. Nous allons donc brièvement explorer ces influences pour situer notre sujet et pour bien comprendre leurs enjeux dans les formulations autour du patient acteur sur le terrain aujourd'hui.

Le point de départ quant à la notion « moderne » du patient acteur/empowerment se situe dans les nouveaux mouvements en psychologie après la Seconde Guerre mondiale. Pendant cette période, en tant que citoyens, nous nous demandions pourquoi certaines personnes avaient « collaboré » et d'autres « résisté ». Ces questionnements ont mis en lumière des discussions philosophiques, politiques, psychologiques et citoyennes autour de l'idée d'autonomie et d'autodétermination. Ils ont conduit au mouvement des droits civiques dans les années 1960 et 1970.

C'est au cours de cette période que les chercheurs et les travailleurs sociaux mobilisent l'idée d*'empowerment* pour la première fois.[4] Barbara Solomon a publié en 1975, « *Black Empowerment : Social Work in Oppressed Communities*[5] » et nous a donné la notion d'empowerment comme un objectif du travail social. Solomon définit « l'empowerment » comme une activité engagée par un travailleur social envers son bénéficiaire. Cette première formulation cherche surtout à aider des groupes stigmatisés à gagner une capacité d'agir. Ce qui ressort de cette première formulation est notre responsabilité sociale pour aider des personnes qui sont « non-actives » (*unempowered*) à devenir actives (*empowered*). Si la personne qui est « non-active » doit participer à ce processus, nous mettons également en jeu la responsabilité de la société lui ménager des possibilités.

Une autre influence importante pour notre compréhension actuelle du patient acteur que nous voudrions souligner vient du brésilien Paolo Freire et de son livre sur l'éducation populaire.[6] Inspiré par la philosophie marxiste, Freire cherche à développer une

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[4] Calvès, Anne-Emmanuèle. 2009. *« Empowerment » : généalogie d'un concept clé du discours contemporain sur le développement. »* *Revue Tiers Monde* 200 (4) : 735.
[5] Solomon, B.B., 1976. *Black empowerment: social work in oppressed communities*. Columbia University Press, New York.
[6] Freire, Paulo. 2000. *Pedagogy of the Oppressed*. 30th anniversary ed. New York: Continuum

compréhension à la fois individuelle et collective de l'*empowerment*. Freire souhaite que la personne développe une conscience critique de l'oppression pour pouvoir en sortir. Cette conscience critique se situe au niveau individuel, dans une conscience critique de soi, mais aussi au niveau collectif, dans l'identification des racines communes de l'oppression. Dans la formulation de Freire, l'*empowerment* devient donc non seulement une activité individuelle à cultiver, mais aussi une activité collective. Cette prise de conscience collective a amené à des mouvements sociaux importants, tels que l'entrée dans l'arène politique des associations de patients.

Cependant, l'application du concept proposé par Freire pose des problèmes pour notre sujet. Liée à la psychologie du développement, la vision de la conscience critique est devenue une méthode pour aider une personne à développer des compétences et des ressources pour devenir acteur. Si nous cherchons souvent à cultiver des capacités à agir chez ces personnes, une fois ces capacités acquises, nous nous attendons à ce qu'il ne reste plus de barrières. Avec l'histoire de Nicolas, nous pouvons déjà voir quels problèmes pose cette vision du patient acteur. Nicolas avait besoin de l'assistance de ses parents et de temps pour pouvoir grandir et bien comprendre sa maladie et son traitement. Même ayant acquis ces capacités, il avait aussi besoin de pouvoir les mobiliser lors de la consultation. C'était grâce à la confiance établie entre lui et son médecin qu'il a pu devenir acteur. Nous pouvons donc comprendre la nécessité d'un environnement propice pour Nicolas.

Examinons maintenant d'autres influences importantes qui ont eu un impact sur la conception du patient acteur et la mise en place des programmes pour favoriser son développement sur le terrain. Ces deux mouvements vont nous mettre en lumière un problème important pour notre discussion : qui décide si le « choix » du patient est bon ? Est-ce le patient lui-même ? Ou bien parlons-nous plutôt de résultats espérés par les institutions de santé, tels que l'adhésion au traitement ? Pour nous aider à traiter cette question, nous voulons souligner deux mouvements politiques qui ont eu un impact sur la conception du patient acteur sur le terrain.

Le premier est le mouvement politique des « New Rights » aux États-Unis et en Angleterre. Cette politique encourage une vision minimaliste de l'Etat et encourage les patients à devenir des « consommateurs » de leurs soins et à « gérer » leur santé de manière autonome. Leur influence s'étend bien au-delà de ces deux pays. Ces courants d'idées ont

eu une influence parfois cachée sur des mouvements souvent considérés comme citoyens tels que le mouvement du « self-help » dans les années 1980.

Le second mouvement politique d'importance pour notre sujet vient des professionnels de santé pendant le mouvement des droits civils. Pendant cette période, des infirmiers et d'autres professionnels de santé revendiquaient de nouveaux rôles spécifiques à leur profession afin de valoriser leurs capacités particulières pour aider leurs patients. Des programmes tels que l'éducation thérapeutique – aujourd'hui une méthode favorisée en France pour aider le patient à devenir acteur – sont parmi les résultats de ces mouvements. C'est ainsi que les professionnels de santé ont organisé ces programmes. D'un point de vue éthique, ces programmes visent à l'apprentissage de la maladie. Cela permet au patient de participer plus activement à ses soins. D'un point de vue économique et organisationnel, cependant, ces programmes visent également à encourager l'adhésion au traitement. Nous sommes donc en présence d'un double enjeu.

Ces enjeux révèlent un problème qui n'a pas été résolu jusqu'à présent dans les discussions sur le patient acteur. Si le mot « acteur » garantit une autonomie du patient pour « gérer » sa maladie comme il le souhaite, en retour nous supposons que les choix du patient sont en harmonie avec le protocole du traitement proposé par le médecin. Nous voulons en éduquant le patient, qu'il soit en adhésion avec ce traitement. Si souvent les deux priorités s'alignent, nous ne pouvons le garantir. Nous découvrons ainsi une tension au cœur de ce sujet. En tant que société, nous souhaitons promouvoir les droits des individus et par conséquence promouvoir le droit de décision pour le patient. En parallèle, nous cherchons à garantir les résultats avec des stratégies telles que l'adhésion au traitement. Laquelle de ces priorités faut-il privilégier sur le terrain ?

Nous faisons le choix de prioriser les patients dans cette recherche. Nous aurons donc besoin d'une nouvelle terminologie et de nouvelles méthodologies pour comprendre comment le patient envisage sa participation.

Méthode 1 : une méthode *basée sur* les émotions

Pour recueillir les contributions des patients sur le terrain, il était d'abord nécessaire de trouver une méthode de recherche en mesure de transformer les patients en sujets actifs. Nous avons voulu développer une méthode qui prêterait attention à la fois à ne pas parler à la place du patient, mais aussi qui permettrait de travailler avec des patients dans une relation de partage et de co-création. Nous avons développé deux méthodes, une méthode *basée sur* les émotions et une méthode *basée sur* les capacités.

La découverte de notre première méthode *basée sur* les émotions s'est faite avec un groupe de parole de patients à Lyon. Le groupe de parole inclut des patients et des familles épileptiques qui se réunissent deux fois par mois pour discuter ensemble de la maladie. Ils viennent souvent au sein du groupe de parole pour « lâcher prise » et pour parler avec d'autres malades afin de mieux comprendre leur maladie et leurs traitements. La plupart des participants au groupe de parole ont une épilepsie pharmaco-résistante, impliquant des difficultés à travailler et à étudier à cause de problèmes de mémoire et de concentration liés à leur maladie – mais aussi au traitement. Les discussions dans ce groupe sont très personnelles, voire intimes, avec des échanges sur les problèmes au travail, avec les familles, avec les amis ou partenaires, et avec les médecins.

Comme je suis venue au groupe de parole pour mieux comprendre l'épilepsie, je me suis présentée en expliquant pourquoi je venais et après je suis restée silencieuse. Comme il était entendu que chacun prenne la parole, j'avais du mal à trouver ma place parce je n'étais pas a priori directement concernée par la maladie. En retour, les participants ont « osé » donner des détails très personnels sur leur vie, tels leurs problèmes au travail, en couple, ou bien les relations avec leurs médecins. Dans cette situation, je n'ai pas pu prendre de notes, car cela aurait été encore plus gênant pour les participants. Dans cet espace limité, il était nécessaire de penser à une méthode qui ne « dérangerait » pas trop les participants, mais selon laquelle je pourrais quand même recueillir ce qui était dit pendant les réunions.

Pour tenir compte de ces contraintes, j'ai décidé de mobiliser une méthode habituelle en anthropologie, l'usage de mots-clés.[7] Cette méthode implique de prêter attention à certains mots récurrents dans une discussion. L'avantage de celle-ci est de permettre de faire attention à certains mots sans pour autant avoir à transcrire mot à mot ce que disent les participants. Identifier des mots-clés est un processus intuitif qui permet de retenir des mots qui nous intéressent au cours des discussions. Cependant, cette méthodologie ouvre également à des « surprises » en faisant porter l'attention sur des thèmes auparavant insoupçonnés. Ce premier terrain a permis de construire une piste de réflexion, puisqu'en écoutant des patients et des familles, j'ai rapidement trouvé un mot-clé, qui est devenu une piste prometteuse pour la suite de la recherche : le mot *peur*.

Dans cette méthode *basée sur les* émotions, il n'était pas question de mesurer la peur, de demander aux patients quand ils avaient peur et pourquoi ils avaient peur. Il était plutôt intéressant d'essayer de prêter attention au moment où les patients utilisaient le mot et pourquoi, et de voir ce que cette émotion pouvait dire de leur *eudaimonia* (épanouissement humain) en s'inspirant des travaux de la philosophe américaine Martha Nussbaum. L'*eudaimonia* est un concept de la philosophie grecque : il est traduit aujourd'hui comme l'épanouissement humain ou bien le bonheur. Ce qui intéresse la philosophe Martha Nussbaum dans le concept de l'*eudaimonia* n'est pas le bonheur spontané tel celui de recevoir de bonnes nouvelles ; elle s'intéresse plutôt à notre capacité à nous épanouir à travers notre vie, en la construisant et en la développant avec les autres. Nous retenons donc la traduction d'*eudaimonia* comme épanouissement humain pour notre discussion.

La théorie des émotions de Martha Nussbaum[8] renverse nos idées reçues. Pour elle, les émotions sont intelligentes. Nussbaum affirme que les émotions ont un objet. Cet objet est un objet d'intention : il est vu ou interprété par la personne concernée. En général, ces objets sont des personnes, des choses, des évènements, qui présentent une importance pour le bien-être de la personne. Nussbaum émet donc l'hypothèse que les émotions sont des *jugements de valeur*. La valeur perçue dans l'objet fait référence à notre propre *eudaimonia* puisque l'objet de nos émotions est important en vertu du rôle qu'il joue dans notre vie.

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[7] Taylor, S.J., Bogdan, R., 1998. *Introduction to qualitative research methods: a guidebook and resource*, 3rd ed. ed. Wiley, New York. P. 55.
[8] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York.

Pour Nussbaum, les émotions nous aident à évaluer ces situations et nous permettent de porter des jugements sur celles-ci. Nous devrons donc prêter attention à des émotions « fortes » comme la peur. Elles ne sont pas irrationnelles ; au contraire elles peuvent nous révéler quelque chose de très importante pour la personne concernée.

Selon la théorie de Nussbaum, l'expression de nos émotions est liée à notre vulnérabilité animale, notre dépendance et notre attachement aux choses qui sont hors de notre contrôle. La genèse de nos émotions s'inscrit dans notre enfance. Nous arrivons au monde dans une situation de dépendance extrême, où nous dépendons des *biens externes* pour notre survie. Au stade du développement où le bébé se rend compte de cette dépendance, il éprouve pour la première fois de la honte. Cette honte est spécifique, liée au manque de capacité à contrôler pleinement la situation et à une reconnaissance de sa propre impossibilité à subvenir à ses besoins tout seul. Cette honte crée une première *ambivalence* chez l'enfant et amène souvent à des émotions fortes. Pour Nussbaum, nos émotions adultes prennent racines dans ces expériences primaires d'ambivalence. Notre ambivalence envers des biens externes continue à être source d'angoisse une fois adulte aussi. La maladie est justement un de ces moments qui cristallisent ces besoins et peut donc être source d'émotions très intenses comme la peur.

Pour Nussbaum, la peur est une émotion destructrice, d'un caractère fort ; cependant, elle n'est pas nécessairement négative. La peur est notre première émotion et une de celles que nous partageons avec les autres animaux. Alors que d'autres émotions telles la compassion dépendent de cognitions sophistiquées, la peur est mise en route par des mécanismes évolutifs. Elle nous aide à échapper aux dangers. Sans peur, nous ne pourrions pas vivre très longtemps. Donc la peur est une émotion particulièrement intense, mais aussi particulièrement utile à notre survie.

Nussbaum dit que la peur implique la conviction qu'un mauvais événement va se produire et que la personne concernée ne peut pas entièrement en atténuer le danger. Cette émotion est donc liée à une perte de contrôle.

Néanmoins, si la peur nous aide à survivre, elle peut aussi devenir destructrice et nous empêcher de vivre. La peur devient problématique surtout quand nos expériences primaires de la peur conduisent à des formes « enseignées » de la peur. Ces peurs « enseignées »

deviennent avec le temps des représentations complexes, de plus en plus difficiles à dénouer de l'expérience primaire de la peur, et peuvent être parfois erronées. Une première expérience de la peur avec un médecin, par exemple, peut amener à une autre peur lors de prochaines rencontres avec le médecin, ou à une évaluation erronée de la peur en dehors de cette relation qui peut nuire à la personne.

En prenant en compte ces réflexions sur la peur, j'ai décidé de comprendre comment et pourquoi les patients et leur entourage ont exprimé de la peur. Je voulais prendre au sérieux cette peur et comprendre son importance pour la personne concernée.

La peur

Dans l'histoire de Nicolas, nous pouvons voir comment la peur amène à des souffrances multiples pour le patient, sa famille, et le médecin. Il y a la souffrance de Nicolas, qui doit soudainement vivre avec l'annonce d'une maladie grave. Nicolas devra apprendre à vivre avec la peur des crises, des crises qui vont dominer sa vie, impacter sa scolarité, son futur emploi, et même peut-être ses futures relations amoureuses. Il doit également apprendre à vivre avec la frustration suscitée par la méthode d'essai-erreur des différentes posologies.

Nous voyons également la peur ressentie par la famille de Nicolas à l'annonce du diagnostic et de l'incertitude du traitement. La mère et le père de Nicolas deviennent acteurs afin d'essayer d'aider leur enfant. Dans la période de recherche d'un « bon » médecin, ils utilisent toutes leurs ressources disponibles pour aider leur fils. Ils sont motivés par la peur.

Nous voyons aussi la souffrance du premier médecin, qui ne sait pas apporter des réponses à son patient, malgré toutes les avancées scientifiques liées au diagnostic et au traitement de la maladie. Admettre l'incertitude devant le patient et sa famille n'est pas seulement difficile, cela met en question son expertise. Cette incertitude est une source de peur. Pour la cacher, il ne regarde ni le patient ni la famille dans les yeux ; cependant, ceux-ci voient sa peur et subissent ses conduites d'évitement.

Toutes les parties concernées par cette histoire souhaitent que Nicolas guérisse, que le médecin trouve la solution miraculeuse à son cas. Cependant, comme cette relation est menée par la peur, elle est une source de souffrance pour toutes les parties impliquées. Nous allons donc étudier ces peurs pour comprendre comment elles affectent le bien-être de nos patients. Nous ferons apparaître par nos arguments que la peur dans ces relations clés amène à une multitude d'actions et de réactions : l'isolement à l'égard de la société, la stigmatisation, la surprotection, mais aussi des erreurs médicales.

La discussion autour de ces peurs multiples dans la vie du patient touche à des peurs humaines et universelles, en soulignant notre vulnérabilité, notre manque de contrôle, et notre besoin de vivre avec les autres en société. Nous allons chercher ici à comprendre ces peurs, au lieu de montrer du doigt le méchant dans l'histoire. Ce qui nous intéresse dans cette analyse sera de révéler ces peurs afin de trouver des solutions pour aider la personne à mieux vivre avec sa maladie. Comme le souligne le philosophe Hans Jonas, ce que la peur devrait nous inspirer, c'est « d'avoir le courage de prendre des responsabilités »[9] à l'égard de ces peurs.

[9] Jonas, H., Greisch, J., 1991. *Le principe responsabilité : une éthique pour la civilisation technologique*, Passages. Éd. du Cerf, Paris. p. 300

La peur du patient : l'épée de Damoclès

Elodie est une jeune patiente qui ne perd pas conscience pendant ses crises. Même si elle ne peut les voir, les autres lui disent que ses crises sont impressionnantes : elle a des convulsions tonico-cloniques, elle crie à pleins poumons et son corps entier se contracte. Pendant la crise, la seule façon de communiquer avec sa famille semble être de crier. Sa famille lui dit toujours de se calmer, mais elle ne le peut pas. L'impossibilité de contrôler son corps lui cause beaucoup d'angoisse. Elle décrit l'état de sa crise comme « une scène d'horreur ».

Une crise d'épilepsie est un manque de contrôle, un corps qui déraille soudainement. Les épileptiques décrivent souvent leur maladie comme « une épée de Damoclès. » Ils vivent avec une incertitude permanente : quand vont-ils faire une crise ? De qui vont-ils être entourés à ce moment précis ? Comment réagiront les autres ? Que se passera-t-il dans leur corps pendant la crise ? Ces moments de perte de contrôle de leur corps sont une source de peur pour la personne épileptique. Quand la personne fait l'expérience de la crise, elle vit une déconnexion entre son corps et le monde. Le corps devient un objet de peur pour la personne et ses témoins. Pour les personnes qui ne perdent pas connaissance pendant leurs crises, elles décrivent cette déconnexion comme « douloureuse » ou bien comme Elodie, comme « une scène d'horreur. » Comme nous le voyons à travers l'histoire d'Elodie, sa peur n'est pas irrationnelle. Elle a un objet précis : la perte de contrôle du corps. Habituellement, notre corps nous permet un accès au monde et aux autres. La personne qui fait l'expérience de la crise vit une expérience de déconnexion entre son corps et le monde. Cette expérience est effrayante.

Dans ces situations, la personne dépend de l'assistance des autres pour être mise hors de danger. Ce besoin – même temporaire - est loin d'être facile à accepter pour la personne concernée. Comme Nussbaum nous le montre, dès l'enfance, nous voulons être autonomes. Pourtant nous vivons dans une vulnérabilité et une dépendance pour subvenir à nos besoins. Notre ambivalence est causée par la provision incertaine de cette assistance, provoquant des émotions fortes comme la peur. L'épilepsie est une maladie qui met en lumière notre besoin récurrent de biens externes, de notre dépendance à l'égard des autres. Confier une responsabilité aux autres pendant la crise, qu'il s'agisse de la famille, des

collègues, des amis ou bien d'étrangers, requiert l'assurance de leur soutien. La peur du corps n'est donc pas seulement une question de manque de contrôle du corps ; elle est également liée à nos relations avec les autres.

En retour, si l'épileptique ne peut se reposer sur aucune aide, il aura une peur encore accrue des crises. L'état d'incertitude quant à l'assistance dont il peut bénéficier peut donc encourager chez lui l'évitement des environnements à risque. Cette incertitude est donc susceptible de générer de nouvelles réactions, telles que de nouvelles représentations de la peur, qui empêchent la personne de poursuivre une vie dite « normale » et d'avoir des relations durables avec les autres.

Selon l'angle d'approche, nous pourrons faire valoir que ces moments sont temporaires, et que le patient peut mettre en place des stratégies pour les limiter. En poursuivant la réflexion autour du patient acteur, nous pourrions suggérer que le patient doit « connaître » sa maladie et trouver des solutions pour éviter les risques potentiels pendant les crises, tel que conduire ou pratiquer certains sports. Tandis que toutes ces stratégies peuvent potentiellement réduire la peur, cela nous mène à un deuxième questionnement : à quel moment le risque est-il plus important que la capacité d'agir…et pour qui ? C'est là le dilemme auquel sont confrontées quotidiennement la personne et sa famille, et il conduit souvent à des comportements de surprotection de la part des proches, comme nous le montrerons plus loin.

Si nous voulons que ces personnes puissent bien vivre avec leur maladie, nous devons chercher des solutions pour leur permettre d'avoir moins peur de leurs crises. Examinons donc comment la société voit la personne avec ses crises et ce que nous pouvons lui proposer pour créer un environnement moins craintif.

La peur de la société

Au lieu d'apporter assistance, la société propage souvent une peur qui nuit à la personne. L'épilepsie est une maladie connue depuis l'Antiquité, et son histoire mouvementée est liée à des réactions sociétales de stigmatisation. Les représentations de l'épilepsie qui l'envisagent comme une contagion, une possession, ou comme une maladie psychiatrique persistent encore dans l'imagination populaire. Même aujourd'hui, les patients et familles continuent à cacher la maladie à cause de ces représentations. Nous proposons de découvrir les sources de la peur de la société envers l'épileptique, à travers le prisme du travail, et son impact sur le patient. Pour montrer la récurrence de ces peurs à travers des histoires différentes, dans des pays et des cultures divers, nous allons prendre un exemple qui vient de Chine.

Mei Ling, une patiente à Shanghai, va nous parler de son expérience de vie :

Mei Ling est « hantée » par son épilepsie, ce dont elle souffre depuis l'âge de 16 ans. Le travail et ses relations avec ses collèges demeurent la partie la plus difficile à affronter. Son chef a compris qu'elle a des problèmes de santé. Il lui permet de prendre des congés pour voir des spécialistes ; cependant, elle n'ose pas lui dire que cette maladie est l'épilepsie. S'il savait, elle est certaine qu'il l'obligerait à démissionner. L'épilepsie continue de faire « peur » en Chine, comme partout dans le monde.

Ses collègues sont moins compréhensifs à l'égard de ses besoins médicaux. Ils ont compris qu'elle a des problèmes de santé, mais ils ne connaissent pas le nom de la maladie. Cette souffrance ne vient donc pas de la maladie en particulier, mais des besoins spécifiques du patient. Comme elle doit parfois quitter tôt son travail pour ses rendez-vous médicaux, ils la disent « privilégiée ». Un de ses collègues a même cessé de lui parler à cause de ce « privilège. » Elle décrit le temps de travail comme une manière « d'être morte. » Sa mère me dit qu'elle est déprimée à cause de ses souffrances subies du fait de ses collègues. Comme elle ne peut pas exprimer sa frustration devant ses collègues, elle se permet d'être agressive envers sa famille.

Son épilepsie n'est pas « sévère » même si elle est pharmaco-résistante. Elle a des crises courtes au cours desquelles elle ne perd pas conscience. Ces crises ne durent que quelques secondes et d'habitude elle récupère très vite. Quand elle a une mauvaise journée, elle peut avoir jusqu'à trois crises, mais habituellement, elle en a beaucoup moins. Ses collègues ne remarquent jamais quand elle a une crise au travail. Elle a même développé ses propres stratégies d'adaptation pour que les crises n'impactent pas son travail.

Le médicament qu'elle prend cause plus de problèmes que ses crises. Comme il a un effet sur sa concentration, elle a déjà dû changer de carrière. Auparavant elle avait un métier valorisé en Chine (elle était comptable), mais maintenant elle doit faire un travail qui demande moins de concentration (elle est travailleuse sociale). Ce nouveau choix de carrière, moins prestigieux à ses yeux, la déçoit ainsi que sa famille. Les activités de loisir qu'elle aimait exercer avant – comme la musique et la peinture – sont également devenues difficiles avec ce médicament. Sa mère pense que le médicament pourrait être lié à sa dépression.

Tous ces facteurs ne font qu'exacerber la situation. Elle s'est isolée de ses anciens amis. Elle ne veut pas se marier, même si elle a peur d'être seule. L'impact sur sa famille est immense. Ils s'inquiètent pour sa dépression, pour son manque de désir de trouver un mari, pour son agressivité envers eux. Sa mère décrit la pression sociale subie par sa fille en société comme un « boomerang. »

Les parents ne parlent pas ouvertement de la maladie de leur fille. Ils ont peur de la réaction du voisinage. Comme elle est fille unique, ils s'inquiètent de ce qui se passera quand ils ne seront plus en vie.

La seule chose positive dans la vie de cette patiente vient de l'association de patients organisée par des infirmières et médecins à l'hôpital où elle est suivie. Le club « Hippocampe », essaie de favoriser les apprentissages concernant la maladie. Pour Mei Ling, même si elle suit ces conseils, elle est convaincue qu'elle ne pourra pas bien vivre sans que changent les attitudes sociétales à propos de l'épilepsie. La nécessité de cacher l'épilepsie à ses amis et à ses collègues rend sa vie pénible.

L'histoire de Mei Ling est douloureuse. À cause de sa maladie et de son traitement, elle ne peut pas faire ce qui la passionne, un métier pour lequel elle a fait de longues études. Elle a également du mal à pratiquer les activités de loisir qu'elle aimait avant à cause de son traitement actuel. Sa non-relation avec ses collègues la fait souffrir pourtant plus que sa maladie.

Ces difficultés au travail ressemblent à beaucoup d'histoires entendues dans le cadre de cette recherche en France et en Chine. Le taux de chômage et de sous-emploi pour les personnes épileptiques excède celui de la population générale. De plus, de nombreuses études montrent la difficulté pour les personnes atteintes d'épilepsie de garder leur emploi.[10] Certaines études démontrent une discrimination ouverte envers les travailleurs épileptiques puisque les employeurs les croient plus à risque en matière d'accidents ou d'absentéisme au travail. Dire ou ne pas dire sa maladie devient donc un enjeu majeur pour ces personnes. Pour toutes ces raisons, au moins la moitié des travailleurs ne révèlent pas leur maladie quand ils postulent à une offre d'emploi. Cependant, comme l'épilepsie est une maladie imprévisible, tout le monde ne peut pas la cacher indéfiniment.

Un sociologue polonais, Zygmunt Bauman[11], nous aidera à éclairer ces difficultés et à mieux comprendre cette peur de la société. Bauman nous affirme que, paradoxalement, dans nos sociétés de libertés individuelles, nous sommes de plus en plus exposés à la précarité et à la vulnérabilité. En retour, dans nos sociétés de performance, nous devons être à la fois « aptes » et « efficaces ». De plus, la responsabilité de notre réussite repose entièrement sur nos épaules. Quand nous n'arrivons pas à nous surpasser, les autres nous blâment, mais nous nous tenons également pour responsables. Si la société ou la famille met beaucoup de pression sur nos choix de carrières, nous aurons tendance à intérioriser cette pression et à en faire une peur personnelle. Comme dit Bauman, nous avons fait une transition d'une « peur officielle » à une peur « faite maison ».

Pourtant la maladie interfère avec la capacité à se surpasser au travail, comme nous avons vu avec Mei Ling. La personne affectée d'une maladie chronique a besoin

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[10] Ficher R. S., Vickrey B. G., Gibson P., et coll. *The impact of epilepsy from the patient's perspective I. Descriptions and subjective perceptions.* 2000; 41 (1):39–51.
[11] Bauman, Z., 2007. *Le présent liquide : peurs sociales et obsession sécuritaire*. Seuil, Paris. P. 78–79.

d'aménagements de poste et de temps pour aller chez son médecin. Pour que ces personnes puissent exiger certains ajustements de la part des employeurs et pour qu'elles puissent s'épanouir dans leurs carrières, il est nécessaire pour ces personnes d'avoir un soutien social de la part de leurs collègues. Au lieu d'accueillir ces différences, nous les autres travailleurs les critiquons comme des « privilégiés ».

Demander d'accepter un individu porteur d'une maladie chronique dans le monde du travail comme Mei Ling révèle nos peurs les plus intimes : notre peur d'être *aussi* vulnérable qu'elle. Nussbaum nous rappelle que les êtres humains sont les seuls parmi les animaux à être angoissés à l'égard du fait d'être des animaux. Nous sommes les seuls qui essayent de surpasser cette vulnérabilité. Avoir peur de la personne malade ne signifie pas nécessairement avoir peur de Mei Ling en elle-même ni de l'épilepsie, mais plutôt craindre sa propre fragilité. Usuellement, nous ne sommes que vaguement conscients de cette fragilité ; la maladie en revanche évoque pour nous cette possible dérégulation de notre propre corps dans un avenir prochain.

Comme Freud constatait, c'est *l'inquiétante étrangeté*[12] que présentent ces personnes que nous souhaitons éviter. Il définit l'inquiétante étrangeté comme quelque chose de terrifiant qui nous ramène à quelque chose de très familier. Dans son article, Freud cite les crises épileptiques comme exemple de ce phénomène. Voir la personne en face de nous qui perd contrôle soudainement est « inquiétant ». Ce sentiment étrange nous rappelle le caractère incertain de notre vie et de nos projets.

Nous pourrions donc comprendre que ces peurs sont humaines, liées à la précarité et à notre propre vulnérabilité. Nous pouvons peut-être les excuser. Cependant, ces peurs vécues en société, et surtout dans le monde du travail, ont un impact nocif sur nos patients et leurs familles, comme nous le voyons avec Mei Ling. Ils deviennent les victimes d'un phénomène de stigmatisation et subissent un isolement social lié à l'exclusion ou à l'expulsion hors du monde du travail. Souvent ces peurs vécues par la société ont aussi un effet nocif sur les crises, puisque les émotions fortes peuvent être un facteur favorisant des crises pour certaines personnes. Ces peurs vécues du fait de la société ont aussi un *effet*

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[12] Freud, S. 1919. *The "Uncanny". Imago,* Bd. V., 1919.

boomerang et deviennent des manifestations complexes et destructrices pour la personne concernée et son entourage. Nous devons donc penser à des solutions.

Nous pensons qu'il faudrait agir au niveau individuel et au niveau institutionnel pour créer un environnement propice pour nos patients. Au niveau individuel, les personnes concernées (les personnes épileptiques, les familles, les médecins…) peuvent faire sortir l'épilepsie « de l'ombre » pour réduire la peur engendrée dans la société. En retour, l'institution peut intervenir pour encourager l'embauche et le maintien en emploi des personnes avec des maladies chroniques qui ont besoin de souplesse ou d'adaptation.

Les peurs actuelles de la société à l'encontre de ces malades empêchent ces personnes de développer et d'utiliser leurs capacités dans le monde du travail, mais plus généralement d'avoir des relations durables avec les autres. Donc le changement ne peut pas s'arrêter là. Si nous voulons vraiment changer le comportement et favoriser l'acception de Mei Ling de ses collègues, de ces personnes avec des maladies qui nous « dérangent », nous devons dès maintenant penser la vulnérabilité au travail d'une manière collective. Penser la vulnérabilité de tous les travailleurs nous aidera tous à mieux vivre avec nos vulnérabilités dans le monde du travail mais aussi à les accepter chez les autres.

La peur au sein de la famille

Nous avons vu les peurs ressenties par le patient et par la société, et l'effet nocif qu'elles ont sur le patient et sa capacité de bien vivre avec sa maladie. Nous devons maintenant nous tourner vers un sujet encore plus douloureux, la peur au sein de la famille. Dans son livre sur les émotions, Martha Nussbaum nous décrit le deuil qu'elle a dû vivre quand elle a perdu sa mère. Pour Nussbaum, cette peur a été particulièrement douloureuse puisque c'était la mort d'une personne irremplaçable dans sa vie.[13] En effet, la mort potentielle d'un être cher est particulièrement difficile à vivre, puisque la personne est intimement liée à notre vie, à nos souvenirs et à nos projets de vie.

La peur qui rend la vie difficile au sein de la vie de famille épileptique est la peur de la mort. La mort subite et inexpliquée dans l'épilepsie représente un risque réel pour la personne épileptique. Un phénomène largement inexpliqué par la communauté médicale, la mort subite cause 10 % des morts des personnes épileptiques.[14] Il est donc possible de mourir d'une simple crise. Cette peur de la mort reste souvent en arrière-plan dans l'imaginaire du patient et de sa famille, mais elle est toujours présente et angoissante. Elle représente l'épée de Damoclès, prête à tomber à tout moment.

En plus de cette inquiétude, assister à la crise dérange les témoins, même ceux à qui elle est familière. Souvent, les familles disent que la crise ressemble « à la mort subite devant leurs yeux. » La crise en elle-même fait peur, même quand la famille sait comment assister son proche. L'objet de cette peur n'est pas vague, comme nous le voyons à travers *l'inquiétante étrangeté* des collègues. Elle est focalisée sur un objet précis : une personne qui nous est chère et que nous avons peur de perdre.

Cette peur de la mort d'un proche amène à diverses stratégies, mais celle qui a l'impact le plus nocif est *la surprotection*. Nous allons donner deux témoignages de patients qui souffrent à cause de cette réaction. Ces deux patients disent qu'ils préfèrent vivre à plein temps dans un centre médical-social (La Teppe) le temps de stabiliser leur épilepsie et de

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[13] Nussbaum, M.C., 2001. *Upheavals of thought: the intelligence of emotions*. Cambridge University Press, Cambridge ; New York. p. 68

[14] Keddie, S., Angus-Leppan, H., Parker, T., Toescu, S., Nash, A., Adewunmi, O., Liu, R., 2016. *Discussing sudden unexpected death in epilepsy: Are we empowering our patients? A questionnaire survey.*

pouvoir trouver leur propre voie. Ceci en majeur parti parce que la surprotection de la part de leurs parents est tellement forte qu'elle élimine toute possibilité d'agir :

- *« Je préfère être ici parce que quand je suis chez ma mère c'est horrible… ma mère me surprotège… quand je lui dis, 'je veux sortir avec les autres,' elle dit toujours 'non, je ne te laisserai pas sortir parce que tu vas avoir des crises et je vais devoir te ramener à la maison.' Elle me surprotège toujours, la maladie lui fait trop peur. Du coup, ici, je me sens plus libre. »*

- *« La Teppe était une voie de secours pour moi… j'ai eu la frousse avant de parler à ma mère, mais vraiment la frousse de ma vie parce que ma mère ne voulait pas me lâcher. Alors quand je suis rentrée ici, elle a fini par accepter, mais le docteur a dit quand vous arrivez ici c'est à condition que vous ne voyiez pas votre mère pendant quatre mois. Pour moi, c'était presque un médicament en fait de passer par là. C'est vrai ! Parce que m'attendre toujours à la maison et rester assise, et faire attention ! C'était coûteux. Finalement* (venir à la Teppe) *a été LA solution au problème. »*

Nous voyons dans ces deux histoires que la surprotection apporte des souffrances pour le patient et pour sa famille. Elle nuit aux relations familiales, et elle impacte la capacité d'agir pour nos patients. La surprotection peut se manifester de différentes façons, mais nous pouvons déjà observer certaines tendances dans ces deux témoignages : une anxiété générale de la part des parents et des actions telles que d'interdire à leur enfant de sortir, lui imposer de rester assise, etc. Lorsque la protection devient excessive, elle limite la capacité de la personne par des restrictions inutiles. Les études de psychologie montrent que les enfants qui vivent une surprotection courent un risque plus élevé de développer des troubles anxieux lorsqu'ils deviennent adultes.[15] La surprotection suggère un monde dangereux et encourage l'évitement. Elle ajoute à la peur du patient, menant à de nouvelles expériences enseignées de la peur. La surprotection conduit également à la création d'une forme de dépendance supplémentaire. Cela devient à la fois stressant pour la personne (qui veut agir, mais devient trop effrayée et se croit incapable) et pour la famille, qui doit

[15] Clarke, K., Cooper, P., Creswell, C., 2013. *The Parental Overprotection Scale: Associations with child and parental anxiety*. Journal of Affective Disorders 151, p. 618.

consacrer beaucoup de temps pour répondre aux besoins du proche dépendant. Cette peur est un autre exemple de l'*effet boomerang*, né de la peur de la famille à l'égard de la maladie, frappant sur son chemin la personne malade, et rejaillissant d'une manière nouvelle au sein de la famille.

Les exemples que nous avons soulignés de la surprotection s'étendent du parent à son enfant. Bien que cette relation soit particulièrement difficile pour les parents, il existe de nombreux exemples d'autres relations familiales et amoureuses affectées par cette surprotection. Nous allons donc donner un dernier témoignage, d'une femme âgée en Chine, qui vit une surprotection de fils à mère. Elle me dit :

- *« Mon fils est très occupé ! En outre, il n'a pas un appartement assez grand pour nous deux, alors je vis seule. Cependant, depuis ma dernière crise, quand je me suis fait mal au supermarché, il m'a dit qu'il ne voulait pas que je sorte. Je reste donc toujours à l'intérieur maintenant, sauf lorsque j'ai un rendez-vous chez le médecin. Il m'apporte mes courses pour que je ne sois pas obligée d'aller au supermarché. "*

Cette patiente est âgée : elle a peu de contacts sociaux depuis qu'elle a perdu son mari. Même si la surprotection de son fils semble bien intentionnée, sa peur à l'égard des crises de sa mère s'est traduite par un isolement social pour son parent. Sa peur a également causé des problèmes en ce qui concerne son traitement. Comme elle perd connaissance pendant ses crises et qu'il n'y a personne à la maison pour témoigner, elle n'en connait pas la fréquence. Cela signifie que personne (le médecin, le patient, la famille) n'est informé de l'efficacité du protocole de traitement. Nous voyons donc que la surprotection peut également conduire à des protocoles de traitement inadéquats. La surprotection s'étend donc au-delà du cadre familial privé et s'avère directement liée au protocole de traitement et à la gestion de son efficacité.

Si nous pouvons comprendre et sympathiser avec la surprotection des proches, nous avons fait le choix de travailler sur le pouvoir d'agir de nos patients. Nous suggérons donc plusieurs solutions pour aider les proches à surmonter cette difficulté. En premier lieu, nous pouvons recommander d'étendre les programmes d'éducation thérapeutique aux familles. Ces programmes peuvent être intégrés dans certaines temporalités avec le patient

ou bien comme spécifiquement conçus en fonction de leurs besoins. Enseigner aux membres de la famille comment aider leurs proches à prendre des risques « raisonnables » les aidera également à découvrir leurs capacités et à avoir moins peur. Les associations de patients peuvent aussi imaginer des groupes spécifiques dédiés aux familles afin de leur permettre de discuter entre pairs des techniques pour surmonter cette surprotection.

La peur dans la relation médecin-patient

Nous avons vu combien la peur est répandue dans la vie du patient. La relation avec le médecin peut donc être une relation privilégiée. Le médecin est celui qui « sait » et « comprend » la maladie. Irving Goffman affirme que le médecin est *l'être sympathique*[16] qui voit la maladie comme ordinaire et ne devrait pas en avoir peur. Cependant, cette relation est également marquée par la peur et amène à des souffrances des deux côtés. Nous allons donc revenir à l'histoire de Nicolas pour comprendre les peurs du premier médecin.

Pour commencer, reconnaître les émotions des soignants demeure un sujet complexe. Les professionnels interviewés dans le cadre de ce travail décrivent la professionnalisation de leur travail comme une activité où, *« nous pouvons aller au-delà des émotions vers des choix raisonnés. »* Malgré le travail récent mené en psychologie, neurosciences, ou en philosophie pour changer notre perspective sur les émotions, elles demeurent largement un sujet tabou pour les travailleurs de soin. Même si nous encourageons les soignants à faire attention aux émotions de leurs patients, les soignants eux-mêmes entretiennent une ambivalence à l'égard de leurs propres émotions, et il existe peu de dispositifs pour les valoriser dans nos institutions.

Dans le soin, les professionnels de santé décrivent souvent les émotions comme « négatives », ou comme « un risque », les empêchant d'atteindre l'efficacité maximale des soins. Nous montrons qu'il est dangereux de tenter d'invalider ces émotions. Les praticiens sont aussi vulnérables, comme leurs patients, et les tentatives pour masquer ce fait sont

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[16] Goffman, E., 1986. *Stigma: notes on the management of spoiled identity*, 26th pr. ed, A Touchstone Book. Simon & Schuster, New York. p. 31.

autant de sources de *burn-out*, *brown-out* et de conflits avec les patients. Nous allons donc creuser ces peurs de la perspective du patient et de son soignant pour essayer de trouver quelques solutions.

D'abord, il est important de souligner que l'épilepsie est une maladie chronique qui met en cause l'expertise et l'autorité des soignants. Etant donné que la plupart des traitements pour l'épilepsie sont prescrits par le biais d'une méthode d'essai-erreur, la plupart des patients interviewés dans le cadre de cette recherche se sont décrits soit comme « un mystère » ou « un cobaye. » Pour le médecin, il va y avoir beaucoup d'incertitude pour décider le protocole de traitement. Le faire admettre au patient et à la famille met en cause son expertise et met en risque ses relations avec ces personnes. Il est compréhensible que ces situations puissent causer de la peur pour le médecin. D'après un patient, *« la possibilité de se remettre en cause, c'est l'ego, un peu. Mais c'est la peur aussi de se remettre en cause. La peur. »*

Nous trouvons un exemple concret de cette peur avec le premier médecin de Nicolas : n'ayant pas la solution, le médecin a préféré éviter toute discussion sur le diagnostic et le traitement. D'après les parents, ce n'était pas « sa peur » qui a été problématique ; c'était la non-communication liée à cette peur. Cette première peur de la part du médecin vient donc, d'après la famille de Nicolas, de la crainte de laisser transparaître un manque de capacité à apporter de l'assistance.

D'autres patients interviewés font également état d'une autre peur de la part des médecins, qui craignent de recourir au mauvais traitement et donc de mettre en danger les patients. L'incitation à « ne pas courir de risques » invite le médecin à ne pas tenter toutes les solutions qui pourraient pourtant conduire à un meilleur traitement. Si nous regroupons ces deux idées de la perspective du patient, ce qui est problématique pour le patient, ce n'est pas que le médecin fasse une expérience de peur. C'est plutôt que cela le conduise à éviter la discussion avec le patient et sa famille.

Les patients ont aussi peur lors de la consultation, une peur due à l'autorité médicale. Ils témoignent d'une réticence à partager des informations potentiellement embarrassantes ou non pertinentes pour le traitement. Par exemple, une patiente qui fait du chant et pense qu'il pourrait y avoir une influence sur ses crises, hésite à le dire à son médecin lors de la

consultation. Ces réticences peuvent être anodines, mais elles peuvent également inciter le patient à cacher des informations nécessaires sur le protocole du traitement, tel que des effets de dépression et même de psychose liés aux médicaments. Ces peurs du patient non seulement empêchent le médecin d'avoir toutes les informations sur son cas, mais « ne pas dire » peut mettre son patient face à des risques.

Nous constatons que ces comportements guidés par la peur dans la relation médecin-patient conduisent à des actions d'évitement. Pour les deux acteurs, la peur peut aboutir à la mise en place de traitements non adéquats, puisque le médecin manque d'informations autour de la maladie, des médicaments, ou d'autres facteurs qui pourraient être nécessaires pour planifier le traitement. La non-communication – que ce soit du côté du médecin ou du patient - ne lui permet pas non plus de comprendre l'impact du traitement sur la vie de ses patients.

Nous pouvons également observer que les deux personnes ne peuvent pas se cacher leurs peurs l'une à l'autre. Quand les patients parlaient de mauvaises relations avec leur médecin, ils décrivaient souvent des gestes physiques telles que, « il a regardé l'ordinateur plutôt que moi, » ou bien « il ne me regardait pas dans les yeux. » En tant que personnes humaines, nos contacts visuels nous connectent les uns aux autres. À la différence des autres espèces, nos interactions sociales dépendent des contacts visuels, qui montrent de l'attention et de l'intérêt. Des patients et leurs familles, devant ce manque de contact visuel, l'identifient comme de la peur. La famille de Nicolas par exemple a identifié la peur dans leur soignant par le manque de contact visuel. En retour, ils ont perdu confiance dans leur médecin à cause de ses actions d'évitement.

Cette peur reste difficile à résoudre. L'incertitude quant au traitement et à son efficacité remet en question la capacité, l'expertise, ou l'autorité du médecin. Du côté du patient, s'il ressent en retour la « peur » de son médecin, il peut continuer à « cacher » sa maladie, ou du moins certains détails importants pour son traitement. Cette peur ajoute aussi à la souffrance et à la peur que vit le patient en société et dans le cadre social et familial. Nous maintenons donc que cette peur doit être résolue pour permettre au patient de devenir acteur.

Afin de combattre cette peur du soignant, nous proposons deux approches. D'abord, certains soignants utilisent la thérapie cognitivo-comportementale (TCC)[17] dans le traitement de l'épilepsie pour aider les patients à éviter les conduites d'évitement, à s'exposer à leurs peurs pour les surmonter. Les facultés de médecine et les établissements de soin peuvent utiliser cette thérapie et d'autres techniques pour aider les soignants à surmonter ces peurs.

Nous pouvons également recommander aux institutions de travailler avec des professionnels de santé et leurs émotions. Une méthode pour effectuer ce travail émotionnel consiste à utiliser des méthodologies qui permettent une discussion à égalité entre confrères, tels que les groupes d'échange entre étudiants ou entre collègues pour réfléchir sur leurs pratiques.[18] Comme ces types de groupes offrent un environnement propice à discuter des émotions dans la pratique de soin, les professionnels de santé peuvent valoriser leurs émotions et celles de leurs confrères dans un environnement sûr. Un tel travail émotionnel peut également avoir lieu à la faculté de médecine pour aider les étudiants en médecine à valoriser leurs émotions avec le soutien de leurs camarades.

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[17] Leeman-Markowski, B.A., Schachter, S.C., 2017. *Cognitive and Behavioral Interventions in Epilepsy*. Curr Neurol Neurosci Rep 17, p. 42.

[18] Tels que les groupes Balint. Voir : Torppa, M.A., Makkonen, E., Mårtenson, C., Pitkälä, K.H., 2008. *A qualitative analysis of student Balint groups in medical education: Contexts and triggers of case presentations and discussion themes.* Patient Education and Counseling 72.

L’importance des émotions pour notre concept de patient acteur

Nous avons poursuivi notre investigation sur la peur afin de comprendre l’importance des émotions vécues par le patient. Nous avons montré que les relations familiales, sociales et médicales sont importantes pour pouvoir bien vivre avec la maladie. Ceci implique que le patient se situe dans le monde, avec les autres, et que la mise en place effective du patient acteur ne relève pas de la seule responsabilité du médecin ou du patient. Nous appelons donc notre approche le *patient acteur de sa vie* afin de prendre en compte ce cadre plus large.

Dans notre recherche, une deuxième méthode nous a permis d’élargir notre recherche après cette première investigation. Elle est inspirée de la théorie *par les capacités*. Avant de décrire cette méthode, nous allons faire appel à deux histoires de patients, au centre médical-social de la Teppe. Ces deux récits nous aideront à situer nos priorités avec nos patients.

L'histoire de Christophe

Christophe, un jeune homme de vingt-deux ans, a un bandage au-dessous de son œil, un rappel d'une crise qu'il a eu il y a quelques jours. Il se présente à moi non pas comme un patient, mais comme un travailleur. Il me dit qu'il travaille dans l'atelier du bois à la Teppe et qu'il est chef de ligne.

Christophe me dit que son épilepsie est pharmaco-résistante, qu'il a tout essayé, mais que rien ne marche. Un traitement gênant pendant son adolescence l'a contraint à peser le gras et le sucre avant chaque repas, ce qui a engendré des contraintes sociales, puisqu'il n'a pas pu manger avec ses amis. Ses souvenirs en amènent à d'autres : il me décrit qu'au collège, il a beaucoup souffert parce que ses amis se moquaient de ses crises et souvent il était exclu de leurs activités.

Tout au long, sa narration mélange le médical et le social. Il dit qu'après cette période, il a vu beaucoup de neurologues, de psychologues ou bien des psychiatres, qui, au lieu de l'aider à aller mieux, ont fait empirer les choses. Après cette période difficile, il a eu un seul souhait : de rester à la maison. Dans son récit, il n'est pas clair sur les raisons pour lesquelles il voulait rester chez lui : est-ce à cause des moqueries de ses « amis » ? Est-ce à cause des difficultés à trouver un bon traitement pour son cas ? Ce qui est clair, cependant, c'est que Christophe était malade non seulement à cause de sa maladie, mais aussi à cause de son traitement en société.

Malgré ses difficultés, Christophe réfléchit à son avenir grâce à l'accompagnant de la Teppe. Il a décidé de rester à long terme dans l'institution, dans un FAM (foyer d'accueil médicalisé), puisqu'il ne peut pas travailler. Rester à la Teppe lui permettra d'avoir l'accompagnement des médecins, mais en même temps de continuer à cultiver ses capacités en travaillant dans l'atelier.

En même temps, son manque d'autonomie dans le service est un problème pour lui. Pour Christophe, cela consiste en des choix sur sa vie quotidienne, comme le fait de prendre ses médicaments d'une manière autonome et de planifier son temps libre. Même s'il vit à plein temps dans une institution, il cherche toujours des moyens d'augmenter son autonomie.

Avec Christophe, même si nous avons parlé de son épilepsie au début de l'entretien, il souhaitait surtout me parler de sa vie, de son travail et de ses amis. Cependant, cela ne voulait pas dire qu'il était passif dans son traitement : il cherchait activement une relation avec son médecin pour pouvoir trouver le meilleur traitement pour son cas.

Quand je lui ai demandé sa définition du patient acteur, il a répondu que c'était pour aider les médecins et les autres patients. Vu la sévérité de son épilepsie, il ne croyait pas qu'en étant acteur, il pourrait s'aider lui-même. Cependant, il voyait dans l'idée du patient acteur un moyen d'aider d'autres patients et son médecin en essayant de nouveaux traitements. Il me dit qu'ainsi il ferait avancer à l'avenir du traitement de la maladie pour d'autres patients.

L'histoire de Mélanie

Mélanie est une jeune femme, avec beaucoup d'énergie. Elle rit beaucoup de fois pendant l'entretien et parle avec franchise, même en évoquant ses difficultés familiales, avec son épilepsie et son long parcours dans les institutions.

Mélanie prend au sérieux sa maladie. Elle a des amis qui sont morts de crises. Elle me dit, « je ne rigole pas sur l'épilepsie. C'est un sujet sensible pour moi, mais je gère… » À cause des risques de sa maladie, elle a appris « les gestes qui sauvent » pour aider ses patients-amis. Elle dit que depuis qu'elle est à la Teppe, elle va très bien : elle a trouvé un ami et elle prépare son avenir.

Comme Christophe, elle ne voyait pas beaucoup d'intérêt à discuter de son traitement. Cependant, comme j'ai un peu insisté, elle m'a montré une connaissance à la fois médicale et expérimentale de son épilepsie. Elle a même compris l'impact que peuvent avoir des émotions sur ses crises. Depuis son arrivée à la Teppe, elle a pu travailler ses émotions et maintenant elle a très peu de crises. Elle m'a même dit que pour le moment, elle a réussi à stabiliser son épilepsie grâce à ce travail émotionnel.

Elle dit que ses crises sont très diversifiées, qu'elle fascine les médecins. Souvent elle se sent comme un cobaye, puisqu'elle a essayé toutes sortes de traitements. Comme avec Nicolas et Christophe, Mélanie a dû vivre avec beaucoup d'incertitude dans sa vie en raison de la maladie. Ce qui l'aide pendant cette période longue et difficile, c'est d'avoir une bonne relation avec ses médecins. Elle participe activement à son protocole de traitement. Elle me dit que pour elle, être acteur veut dire décider du traitement avec son médecin et sa famille. Elle s'approprie la décision à la fin, mais elle insiste sur l'importance de sa famille et de son médecin pour la guider.

À un moment de l'entretien, impressionné par sa connaissance approfondie de son épilepsie et de son traitement, je lui ai dit qu'elle semblait avoir suffisamment d'informations pour faire ses propres choix quant à son traitement. Elle m'a répondu en me disant que son médecin et sa famille l'aidaient à prendre ces décisions et qu'elle ne pouvait pas et ne voulait pas les faire toute seule.

Quant aux conceptions actuelles du patient acteur, Mélanie est l'idéal que les définitions actuelles du patient acteur envisagent : elle donne son opinion au médecin, elle participe à la prise de décisions sur son traitement et elle a appris des stratégies efficaces pour vivre avec sa maladie. Tous ces facteurs, comme avec Nicolas, lui ont permis de stabiliser son épilepsie. Cependant, nous ne pouvons pas vraiment parler d'un partenariat égal. Le médecin, avec sa connaissance médicale, propose une solution et essaie de la convaincre. Mélanie pèse le pour et le contre dans le contexte de sa vie et décide avec l'aide de sa famille. Elle est actrice parce qu'elle s'approprie le protocole du traitement comme étant le sien, mais elle est surtout actrice en relation. Cependant, elle parle d'une manière active, de faire ses propres choix, quand elle parle de sa relation avec son amoureux et de ses futurs projets de travail.

L'histoire de Christophe est plus douloureuse. Il n'a pas réussi à trouver un traitement adapté à son cas. Il participe aux échanges avec les médecins, avec les psychologues, avec ses éducateurs, et pourtant ses crises continuent et même empirent. Christophe est acteur de la prise de décisions, mais ceci n'amène pas forcément à des « bons résultats. » Cependant, il parle d'une manière énergique de son travail dans l'atelier, de la possibilité d'acquérir une spécialisation et une passion pour son travail.

Ce qui intéresse le plus ces jeunes, malgré ces difficultés, n'est pas (seulement) la possibilité de décider de leur traitement. Ils voulaient me parler surtout de leurs possibilités de décider de leur vie, que ce soit au travail, dans leurs loisirs et dans leurs relations avec les autres. En d'autres termes, ces deux jeunes sont surtout acteurs quand ils *planifient* et *mettent en œuvre* leurs projets de vies.

L'approche par les capacités

En prenant en compte nos deux histoires, nous allons maintenant cheminer vers notre approche de patient acteur de sa vie. Pour cette tâche, la théorie de justice *par les capacités*[19] nous aidera à éclairer les perspectives de ces deux patients, ainsi que les autres récits mentionnés dans cet exposé.

Initiée par l'économiste Amartya Sen, et ensuite conceptualisée en philosophie par Martha Nussbaum, l'approche *par les capacités* est inspirée du décalage qui existe entre la ressource brute (le PIB) d'un pays et la réalité de ce que les personnes dans ce pays peuvent vraiment faire. Par exemple, une personne atteinte d'épilepsie vit dans un pays riche comme les Etats-Unis où le système de soins peut garantir une bonne prise en charge de sa malade. Mais il est pauvre et ne peut pas se permettre une mutuelle complémentaire. Puisqu'il il n'est pas en capacité de payer ses traitements, il n'a pas la capacité d'être en bonne santé. L'approche par les capacités s'intéresse donc aux opportunités réelles pour les personnes d'*être* et de *faire* (leurs capacités) dans leur environnement.

Cette approche de justice laisse ouverte l'idée de savoir comment les personnes vont utiliser leurs capacités une fois acquises. Elle reconnaît ainsi le droit des personnes individuelles à décider des conditions de leur vie bonne. Comme nous l'avons vu au début de cet exposé, les idées actuelles concernant le concept de patient acteur essaient d'encourager certains choix faits par des patients, qui sont vus comme « bons » dans une perspective biomédicale et économique. L'approche par les capacités est donc une approche plus respectueuse des choix du patient, puisqu'elle se penche sur l'aptitude des patients à développer et à utiliser leurs propres capacités comme ils le souhaitent. Il s'agit

[19] Nussbaum, M.C. *Creating capabilities the human development approach*, New Delhi, Orient Blackswan, 2011.

donc de développer ces capacités chez nos patients, mais après leur avoir laissé le choix de ce qu'ils peuvent faire avec celles-ci. Comme Nussbaum dit, nous nous intéressons à la manière de rendre des êtres « *concepteurs et constructeurs de leurs propres vies*. »[20]

L'affiliation est une capacité particulièrement importante à cultiver dans la théorie *par les capacités*. Pour Nussbaum, notre capacité d'affiliation nous permet d'être respectés comme un être social. Il s'agit de pouvoir vivre *avec* les autres, mais aussi *pour* les autres. Pour penser aux moyens de mettre en place les capacités dans nos sociétés, il faudra donc penser aux conditions du vivre ensemble et du « prendre soin » les uns des autres. Ainsi comme nous l'avons déjà exposé concernant la réception des personnes épileptiques au travail, si nous souhaitons que nos patients vivent bien au travail, nous devons inclure leur accueil auprès de leurs collègues.

Dans l'approche par les capacités, chaque personne est aussi capable de vivre *pour* les autres. D'après Nussbaum, des personnes traditionnellement vues comme « coûteuses » pour la société, comme les personnes avec des handicaps sévères, contribuent d'une manière réciproque à notre société dans son ensemble. Ainsi comme nous l'avons vu avec Christophe, celui-ci comprenait le « patient acteur » non pas comme un moyen de s'aider lui-même, mais d'aider les autres patients et les médecins. Avec Christophe nous avons donc déjà éclairé sa contribution sociale malgré son handicap sévère. Dans l'approche *par les capacités*, notre responsabilité sociale sera de cultiver au maximum le potentiel de toutes les personnes et de faire notre mieux pour les intégrer dans la vie sociale, puisqu'elles contribuent aussi à nous aider tous à bien vivre en société.

[20] Notre traduction. En anglais, Nussbaum dit, "the designers and makers of their lives." Voir : Nussbaum, M.C., 2008. *Women and human development: the capabilities approach*, 13. print. ed, The John Robert Seeley lectures. Cambridge Univ. Press, Cambridge. p. 284-285.

Méthode 2 : une méthode *basée sur* les capacités

En référence à cette théorie, nous avons développé une seconde méthode de travail pour nous aider à analyser les contributions des patients eux-mêmes autour du patient acteur. Pour élaborer cette méthode, nous avons pris appui sur notre recherche menée au centre médical-social de la Teppe. Ce terrain nous a permis d'avoir une période de recherche de longue durée. Sur ce site, nous avions pu interviewer à la fois des patients et des soignants, ce qui nous permet aujourd'hui d'offrir une vision plus large du patient acteur en incorporant les deux perspectives. Nous allons brièvement exposer nos résultats principaux obtenus par cette méthode, afin de montrer la pertinence de l'approche par les capacités dans la perspective des patients.

Être en bonne santé

Ce qu'est *la bonne santé* continue à interroger les médecins et les philosophes et suscite un vif débat. Cependant pour les patients de la Teppe, être en bonne santé peut être entendu en trois sens : lorsque la maladie n'est pas active (ils ne sont pas en crise) ; lorsque la maladie est stabilisée ou guérie (ils n'ont plus de crise au quotidien) ; ou bien lorsque la personne est capable de planifier et mettre en place ses projets de vie, malgré la persistance des crises ou les effets secondaires des médicaments.

Nous voyons ici l'espoir de nos patients de pouvoir faire disparaître les crises au quotidien. Nous remarquons que les patients aspirent à mettre en œuvre eux-mêmes leurs projets de vie, ce que les crises empêchent souvent. Nous pouvons donc comprendre qu'être en bonne santé est relié à leur capacité à planifier et à poursuivre leurs projets de vie, comme cela est suggéré dans l'approche *par les capacités*.

Même s'il diminue le nombre de crises, nous pouvons retenir de ces éclairages que le traitement n'est pas adapté s'il empêche les patients de rester actifs. Nous avons déjà vu cela avec l'histoire de Nicolas : le bon traitement pour son cas vient du second médecin qui a choisi un traitement qui ne pouvait pas complément arrêter les crises, mais qui permettait à Nicolas d'être actif. Nous proposons donc avec l'aide de nos patients un seuil de bonne santé: être *capables de planifier des projets de vie*. Si nous prenons cet aspect comme le

point de départ du traitement, nous pouvons construire une vraie alliance thérapeutique avec le patient et avec sa famille.

Pour nos patients, être acteur lors la consultation consiste donc à être *capable* de travailler en collaboration avec le médecin pour décider d'un traitement *acceptable*. Le terme *capable* nous signale que le patient doit pouvoir être traité comme une personne digne de respect, lui permettant de participer à la décision du traitement. Le mot *acceptable* souligne que le traitement proposé lui permet de construire un projet de vie en parallèle.

Connaissance de la maladie

Malgré des problèmes sévères les plongeant dans la vulnérabilité et la dépendance, les patients à la Teppe cherchaient à être acteurs de leurs vies. Développer des connaissances sur leur maladie relève d'un des moyens les plus efficaces pour permettre à nos patients d'y arriver. Dans un premier temps, ces connaissances sont une façon de diminuer la fréquence des crises, et donc d'être en bonne santé. Comme nous le voyons dans l'histoire de Mélanie, son travail sur ses émotions lui a permis de stabiliser son épilepsie. Comme elle était en meilleure santé, cette connaissance lui a permis ensuite de pouvoir planifier sa vie, ainsi que d'entrer dans une relation durable avec un autre patient. Avec Christophe, ses connaissances ne lui ont pas permis de stabiliser ses crises, mais elles ont facilité la mise en œuvre de ses projets de travail dans l'atelier. Les deux sont acteurs, développant des connaissances sur leur maladie, afin d'imaginer des possibilités réalistes pour poursuivre leurs projets de vie.

La relation patient-patient

Finalement, nous voudrions nous attarder sur un aspect du patient acteur souvent oublié dans nos conceptions actuelles : l'affiliation existant entre patients. Plusieurs patients, comme Christophe, ont défini le patient acteur comme une manière d'aider les autres patients. Nos patients parlaient de partager des expertises sur un traitement, en participant à la recherche expérimentale pour aider d'autres patients, ou encore en se positionnant en tant que soutien moral pour les autres patients.

Comme l'approche par les capacités, ces perspectives suggèrent l'importance de la réciprocité pour nos patients, souvent vus comme des « bénéficiaires » d'assistance. Mélanie, ayant vu des amis mourir à cause des crises, a fait de son mieux pour apprendre des gestes qui sauvent ; Christophe cherchait à aider les autres patients en essayant des traitements expérimentaux ; et Nicolas devenait une ressource à son école pour sensibiliser les élèves à l'épilepsie. Par tous ces moyens, nos patients contribuent d'une façon active à notre société et apportent de l'aide aux autres, malgré leur handicap.

N'est-il pas temps de les voir ainsi ?

Le patient acteur de sa vie

Forte des contributions des patients, nous voulons maintenant proposer notre définition du patient acteur de sa vie. À travers notre analyse, nous voyons que la priorité principale du patient est de pouvoir développer et planifier ses projets de vie. Notre approche du *patient acteur de sa vie* dépasse donc le cadre du soin.

Un cadre important à prendre en compte est la possibilité d'un environnement propice à leur capacité d'agir. Lorsque les patients ne peuvent pas mobiliser leurs capacités dans leurs environnements, que ça soit lors de la consultation médicale, au travail, ou avec des amis, ils détiennent des capacités, mais ils ne sont pas *capables* d'en user. Il faut donc penser une responsabilité collective afin d'aider les patients à devenir acteurs, que ce soit au travail, à l'école, ou lors de la consultation. Notre proposition est la suivante :

L'approche « patient acteur de sa vie » : *il s'agit d'un cadre conceptuel aux usages multiples, qui souhaite encourager, à un seuil minimal, l'épanouissement des patients malgré leur maladie. Dans cette approche, que ce soit les personnes ou les groupes impliqués, ce sont tous ceux qui peuvent aider les patients à bien vivre avec leurs maladies, y compris les proches, les soignants, d'autres patients, les employeurs et la société dans son ensemble. La politique publique dans l'approche PLE sera axée sur le développement de lois et d'institutions pour aider les patients à développer leurs capacités.*

Les patients recevront une aide à l'élaboration et à la mise en œuvre de leurs capacités de la part de ces acteurs et de ces institutions. Toutefois, cette aide sera apportée en respectant les besoins propres de chaque individu. Cette assistance peut notamment aider les patients à adapter leurs projets de vie en raison des limitations imposées par leur maladie. Nous pouvons suggérer par exemple de mettre en place des enseignements et des lieux de travail adaptés, des programmes aidant les membres de la famille à soutenir le patient, etc.

Dans le cadre de la consultation, l'approche visera à aider les patients et les médecins à collaborer pour élaborer des plans de traitement acceptables pour le patient. Par acceptable, nous entendons un traitement qui permette aux patients de poursuivre leurs projets de vie.

L'objectif ultime de cette approche est d'aider les patients à atteindre un état de bonne santé (selon un seuil minimal), et ce malgré leurs maladies. Le seuil dans notre approche consiste en une capacité à vivre avec les autres dans le cadre de relations sociales et de pouvoir poursuivre leurs projets de vie.

La famille actrice

Nous voulons aussi proposer une définition de *la famille actrice*. Notre démarche investit la famille d'un rôle important pour soutenir ses proches dans leurs projets de vie. Cependant, il reste essentiel de garantir que la peur ne prenne pas le dessus dans cette relation, provoquant la surprotection de la part des proches. Nous proposons donc la définition suivante pour l'approche de famille actrice :

L'approche « famille actrice » : *il s'agit d'un cadre conceptuel qui cherche à établir le rôle primordial de la famille ou autre proche quant à l'épanouissement des patients, en fonction de leurs capacités. Dans l'approche, les familles participent avec le patient, le professionnel de santé et d'autres personnes à soutenir leur proche, si cette assistance est requise par le patient lui-même. Soutenir le patient ne signifie toutefois pas de prendre la place du patient, que ce soit dans ses choix de vie ou dans son traitement.*

Implications pour les institutions

Dans notre conception du *patient acteur de sa vie* et *famille actrice*, nous avons besoin de penser nos institutions — les institutions de soin et les autres — comme un cadre pour encourager la capacité d'agir des personnes. Comme la diversité des relations dans sa vie influence la personne, nous pensons qu'il est primordial d'impliquer un plus large éventail de personnes concernées, tel que les employeurs et les familles, comme nous avons suggéré avec les discussions autour de la peur.

Nous avons un bon exemple de cet accompagnement avec le cas de Nicolas. Nous avons vu que le second médecin a laissé à l'enfant le temps de grandir et de développer des connaissances de sa maladie. Avant qu'il soit prêt à pleinement participer dans la rencontre, il a pu observer les discussions autour du traitement menées avec sa famille et son médecin. Il a vu lors de ces rencontres qu'il était possible pour sa famille de discuter librement avec le médecin. Quand il a pu enfin bien comprendre sa maladie et son traitement, le médecin lui a permis d'avoir une participation active. De plus, la famille a su donner l'initiative au patient en le lui laissant voir son médecin seul. Le médecin et la famille de Nicolas ont ainsi favorisé ses capacités et la possibilité de les utiliser lors de la consultation. Ceci est le rôle facilitant que nous cherchions pour les familles et pour les soignants à travers notre approche.

Nous accordons dans notre approche un rôle important aux soignants pour favoriser le patient acteur de sa vie au sein de leurs institutions. Les soignants peuvent favoriser le rôle actif pour du patient lors des rencontres, mais aussi aider le patient à développer ses capacités pour être acteur. Si nous pensons au cadre plus large de la vie du patient, nous aurons aussi besoin de mobiliser les expertises des professionnels médicaux (médecins, infirmiers…), mais aussi ceux qui peuvent travailler avec le patient dans l'élaboration de projets de vie (éducateurs, psychologues…).

Si Mélanie et Christophe peuvent maintenant envisager de travailler, c'est grâce à l'accompagnement multidisciplinaire de la Teppe, qui les encourage à la fois à développer leurs capacités mais aussi à expérimenter et à découvrir ce dont ils sont capables. La

possibilité d'expérimenter des ateliers, des stages, et des sports les aident à voir que, malgré le handicap, ils sont aussi capables d'être acteurs de leur vie.

Pour ce faire, nous ne pouvons pas imposer des temporalités – parfois courtes, ou même urgentes dans nos institutions – à nos patients. Les institutions de soin doivent trouver des solutions pour accompagner les patients à leurs rythmes et suivant leurs temporalités propres. L'approche *par les capacités* est une approche de longue durée, qui se développe dans le temps et suivant les besoins de chaque individu. Pour avoir un exemple concret, l'accompagnement à la Teppe à travers le « projet personnalisé » permet à chaque patient de prendre le temps nécessaire pour lui de développer ses capacités afin de décider de ses projets de vie.

Les acteurs du soin doivent en retour être soutenus pour favoriser l'approche du *patient acteur de sa vie*. Se contenter de proposer une méthodologie pour les soignants est un projet voué à l'échec ; une méthodologie axée essentiellement sur le rôle des patients échouera lorsque les soignants seront empêchés de travailler. Pour permettre la mise en place d'une capacité d'agir à la fois pour les soignants et pour les patients, il faudra aussi prendre en compte la question de savoir comment « soigner nos institutions. »[21] Des lois qui établissent un cadre de travail qui permette de travailler de manière active avec le patient facilitent cette démarche. Cependant, nous devons également penser des espaces et des architectures d'hospitalité[22] pour permettre à cette alliance thérapeutique de voir le jour.

En suivant l'approche par les capacités, nous soulignerons que la responsabilité sociale implique d'aider le patient à devenir acteur, de la manière dont il le souhaite.

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[21] Oury, J., 2007. *Psychanalyse, psychiatrie et psychothérapie institutionnelles*. VST - Vie sociale et traitements 95, 110–125

[22] Voir: Pierron, JP. *« Pour une philosophie de l'attention spatiale. Architecture des soins et soin de l'architecture.»* Dans: Barrère, C., 2019. *Cahiers thématiques: architecture et paysage, conception, territoire, histoire, matérialité*. p. 137.

Conclusion

Nos approches du patient acteur de sa vie et de la famille actrice intègrent les contributions des patients pour comprendre leurs besoins pour leur permettre de bien vivre avec leurs maladies. Ces approches entendent modifier le point de départ et le centre des discussions autour du patient acteur au patient, en redéfinissant leurs besoins, et ce qu'ils cherchent dans leurs soins et dans leur vie globale. En sollicitant les perspectives des patients, nous avons compris que les patients cherchent un moyen de pouvoir décider de leurs vies et de pouvoir vivre avec les autres en société. Cependant, cette interaction continue bien souvent d'être nocive à cause de la peur, comme les témoignages des patients nous l'ont montré.

Notre concept implique de considérer une plus grande responsabilité sociétale, et nous éloigne d'une conception individuelle de la responsabilité, aussi bien pour le médecin que pour le patient. Les soignants sont souvent frustrés de ne jouer qu'un rôle minime dans le succès du traitement. Les patients sont également frustrés de devoir vivre leurs maladies dans des environnements toxiques pour leur santé. Pour répondre à ces problématiques concrètes, notre conception du *patient acteur de sa vie* est construite pour permettre de penser le rôle des autres dans l'épanouissement du malade dans la société.

Travaux à venir

Étant donné les dimensions économiques du soin aujourd'hui, il reste primordial de s'interroger sur les économies en matière de coût qui seront potentiellement permises par notre approche. Nous suggérons une analyse qui tendra à considérer le patient comme un agent économique à part entière, afin de pouvoir évaluer le coût réel des patients pour la société, notamment lorsque la peur a pour effet d'exclure le patient du monde du travail. Les calculs actuels qui visent la fréquence des hospitalisations liées à la non-adhésion ne permettront pas de comprendre si le patient est réellement acteur. Nous avons besoin de nouvelles méthodes.

Dans nos travaux à venir, nous voudrions également interroger la pertinence de notre approche pour d'autres maladies aiguës et chroniques. Cette démarche aura pour but d'énoncer les besoins spécifiques pour les patients et leurs familles. L'approche du patient acteur de sa vie devra être assez souple pour permettre des modifications et de nouvelles conceptualisations à même de s'adapter à de nouveaux groupes de patients.

Une autre perspective va élargir notre méthode avec les émotions, pour nous permettre d'en identifier d'autres, telles que la honte, le dégoût ou la surprise, et leur importance dans la relation de soin. La peur a été une émotion particulièrement troublante pour le patient épileptique, mais nous pensons que l'identification d'autres émotions à travers d'autres maladies chroniques apportera de nouvelles pistes de réflexions pour notre approche. Comme Nussbaum nous l'a montré, les émotions sont des jugements importants sur notre monde et entretiennent un lien direct avec les valeurs qui nous animent. Il est désormais temps de les privilégier dans la relation du soin.