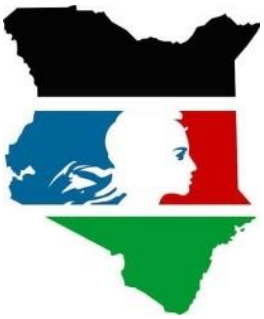
**Laboratoire ITEM EA 3002**
**École Doctorale**
**Sciences Sociales et Humanité 481**
**Université de Pau**



# THE SOCIO-CULTURAL MEANING OF DEATH FROM HIV/AIDS: IT'S INFLUENCE ON HIV/AIDS PREVENTION AMONG THE ABAGUSII-KENYA

Présentée par **MASITA, Ednah Nyanduko**

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**(Spécialité : Anthropologie/Ethnologie)**

**Directeur de thèse : M. Abel KOUVOUAMA**, Professeur des Universités, Université de Pau et des Pays de l'Adour

**Membres du Jury :**

**M. THIBON Christian,** Professeur des Universités, Université de Pau et des Pays de l'Adour

**M. KOUVOUAMA Abel**, Professeur des Universités, Université de Pau et des Pays de l'Adour

**Mme KOTOBI Laurence-Donia,** Maître de Conférences - HDR, Université de Bordeaux

**M. MAUPEU Hervé,** Maître de Conférences, Université de Pau et des Pays de l'Adour

**Rapporteurs :**

**Mme MOULIN, Anne-Marie,** Directrice de recherche émérite CNRS, (UMR 7219/ CNRS

**M. YENGO Patrice,** HDR, IMAF, Ecole des Hautes Etudes en Sciences Sociales – Paris

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**LIST OF ABBREVIATIONS**

| | |
|---|---|
| ABC | ABSTINENCE, BEING FAITHFUL, CONDOM USE |
| AIDS | ACQUIRED IMMUNE DEFICIENCY SYNDROME |
| ART | ANTIRETROVIRAL THERAPY |
| CBOS | COMMUNITY BASED ORGANIZATIONS |
| HAART | HIGHLY ACTIVE ANTIRETROVIRAL THERAPY |
| HIV | HUMAN IMMUNODEFICIENCY VIRUS |
| IPA | INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS |
| ITCZ | INTER-TROPICAL CONVERGENCE ZONES |
| KANCO | KENYA AIDS NGOS CONSORTIUM |
| MTP | MEDIUM TERM PLAN |
| PMTCT | PREVENTION OF MOTHER-TO-CHILD TRANSMISSION |
| SAPS | STRUCTURAL ADJUSTMENT PROGRAMMES |
| STD | SEXUALLY TRANSMITTED DISEASES |
| UNDP | UNITED NATIONS DEVELOPMENT PROGRAMME |
| WHO | WORLD HEALTH ORGANIZATION |

**ABSTRACT**

This study sought to explore the socio-cultural meaning of death from HIV/AIDS among the Abagusii-Kenya. Shaped by the social constructivist ontology and interpretative epistemological approach, the study specifically investigated the socio-cultural meanings of death from HIV/AIDS, the lived experiences of dying from HIV/AIDS and how lived experiences of dying and death from HIV/AIDS influence HIV/AIDS preventive action at individual and community level. The study used data collected from in-depth conversational interviews and participant observation from 50 HIV seropositive people who were arrived at through saturation method and selected through snowball and purposive sampling techniques. Augmentative data was also obtained from purposively selected nine key informants using an interview guide. Data from in-depth conversational and key informant interviews were tape recorded, transcribed ad verbatim and thematically analyzed. Findings from the study showed that at individual level, dying from HIV/AIDS was constructed as a biographical disruption, thus forcing those infected with HIV to undergo existential reorientation by making new arrangements and quests for their new life as a way of achieving a sense of cultural, social and moral belonging to their cultural social networks. At community level, death from HIV/AIDS was constructed as "bad death" in relation to traditional and Christian religious belief discourses governing life, death and after life. As a consequence, such death was perceived as a threat to the corporate social identity and solidarity, and to the regeneration of the community through social reproduction. The study further found that social actions towards dying and death from HIV/AIDS was not based on biomedical knowledge alone but on social relationships especially kinship relations as collectively defined in moral and social discourses of personhood. In conclusion, the study argues that cultural beliefs and values governing life and death should be taken into account in dealing with HIV/AIDS risk prevention in particular cultural contexts.

**RESUME**

Cette étude a cherché à explorer les significations socio-culturelles de la mort provoquée par le VIH/SIDA parmi les Abagusii du Kenya. Façonnée par l'ontologie sociale constructiviste et l'approche épistémologique, l'étude a spécifiquement cerné les significations socio-culturelles de la mort causé par le VIH/SIDA, les expériences vécues de la mort du VIH/SIDA et comment ces expériences vécues influencent l'action préventive au niveau individuel et collectif au regard du VIH/SIDA. L'étude a utilisé des données recueillies à partir d'entretiens conversationnels approfondis et de l'observation participante de 50 personnes séropositives pour le VIH qui étaient sélectionnées à travers la méthode de saturation et sélectionnées par des techniques d'échantillonnage en boule de neige et d'analyse raisonnée. Des données supplémentaires ont également été obtenues à partir de neuf informateurs clés choisis à dessein en utilisant un guide d'entretiens .Les données provenant d'entretiens approfondis et d'entretiens avec des informateurs-clés ont été enregistrées sur bande, transcrites ad verbatim et analysées thématiquement. Les résultats de l'étude ont montré qu'au niveau individuel, mourir du VIH/SIDA était une perturbation biographique, forçant ainsi les personnes infectées par le VIH à subir une réorientation existentielle en faisant de nouveaux arrangements et des quêtes pour leur nouvelle vie afin d'acquérir une sorte d'appartenance culturelle, sociale et morale à leurs réseaux sociaux culturels. Au niveau communautaire, la mort par le VIH/sida a été érigée en «mauvaise mort» par rapport aux discours traditionnels et chrétiens sur les croyances religieuses régissant la vie, la mort et l'après la vie. En conséquence, une telle mort était perçue comme une menace pour l'identité et la solidarité sociale et collective, ainsi que pour la régénération de la communauté à travers la reproduction sociale. L'étude a également révélé que les actions sociales en faveur de la mort et du décès dues au VIH/ SIDA ne reposaient pas sur des connaissances biomédicales, mais plutôt sur les relations sociales en particulier les relations de parenté comme défini collectivement dans les discours moraux et sociaux de la personnalité. En conclusion, l'étude soutient que les croyances culturelles et les valeurs régissant la vie et la mort devraient être prises en compte dans la prévention du risque de VIH/SIDA dans des contextes culturels particuliers.

## GENERAL INTRODUCTION

Kenya is a country in East Africa along the Equator and bordering the Indian Ocean on the East. It neighbours Uganda to the West, Somalia to the East, South Sudan on the Northwest, Tanzania on the South West and Ethiopia on the North. Its capital city is Nairobi. It gained her independence from the British in 1963 with Jomo Kenyatta as the first president. Internally it is administratively divided into 47 counties with each county governed by a governor who is elected through popular suffrage every five years.

In Kenya, HIV/AIDS has continued to be a major socio-economic and medical problem since its advent in 1980s. The disease is one of the leading causes of morbidity and mortality especially among young people who are at the peak of their productive age (Masita, 2011; Masese, 2011). Due to this, the disease has exerted an enormous toll on the socio-economic development of the country (Kamaara, 2005; MoH, 2005; Kwena, 2002).

To mitigate the negative impacts of HIV/AIDS, the Kenyan government has continued to embark on massive prevention intervention campaigns and increasing access to treatment. At the onset of HIV/AIDS, prevention campaigns were based on the Health belief model, reasoned action/planned behaviour theory with the sole objective of empowering people with knowledge on the dominant modes of transmission, ways of avoiding the risk of HIV/AIDS infection and the consequences of HIV/AIDS infection which is death. This was premised on the assumption that people fail to adapt new ideas or respond positively to risky situations because of lack of information.

However, studies by Rugelema, 2004; Campbell, 2004 and Parker, 2001 established that there is no direct link between knowledge and HIV/AIDS risk avoidance. This is because more people continue to be infected despite their level of knowledge about HIV/AIDS being high. Consequently, HIV/AIDS intervention strategies started focusing on structural factors influencing sexual risk behaviour (Hunter, 2002; Gupta, 2002; Campbell *et al.* 2001) and cultural meanings of sex and sexual practices in various cultural contexts (Chitando, 2008; Hunter,2004). Other studies have also focused on the

prevention structures and processes of meaning formation with regard to sex and HIV/AIDS strategies (Masese, 2011). The common denominator in all these studies is that they aim at making HIV/AIDS prevention strategies centered on sexual behaviour effective. However, there is lacuna in all these studies, on how the social construction of HIV/AIDS risk which is death influence peoples' actions towards HIV/AIDS in a particular cultural context.

Unlike other deaths, HIV/AIDS death is emotive, moralized and socially stigmatized. This moralization is due to the fact that in many communities in Sub Saharan Africa death from HIV/AIDS is mostly constructed through the dominant belief systems of Christianity and traditionalism as resulting from sinful acts or acts of immorality which in themselves constitute barriers to entry into afterlife. Both belief systems adopt a puritan approach to death where 'good' death is one which ensures life after death. Death from or in acts such as sexual immorality leads individuals to hell (Elias, 1993), and even in traditional belief systems, people who die through such acts cannot join the ancestral world of immortality.

In studying the social-cultural meaning of death from HIV/AIDS, this study is cognizant of the fact that death is not just a natural fact but also a social fact. As a social fact people make sense of death through various discourses, ideologies, structures and social norms within their social network or cultural context. Among the Abagusii, for example, death is a social process which determines individual identity and status. This identity and status transcends death and is dependent on the type of death (Masese, 2011; LeVine, 1982).

Due to the fact that death from HIV/AIDS is stigmatized and bestows to an individual a spoilt identity, this type of death is perceived as a "bad death". Therefore in this study it is postulated that such meanings of death from HIV/AIDS play a critical role on how people respond to and make sense of HIV/AIDS prevention strategies in efforts to meet the community defined "good" identity. This understanding is therefore critical in

HIV/AIDS intervention programmes since death is taken as an end result of HIV/AIDS infection.

Mbiti (1970) argues that African people see man in two main parts: the physical part which at death is put into the grave or otherwise disposed off, and the non-physical part which survives and bears the personality of the individual in the hereafter. Mbiti continues to argue that the spirit world is a complete copy of the physical world, and it is not removed from the latter. It is a land of rivers, hills, animals, etc; and the activities of its inhabitants resemble those of people in real life, such as working in the fields, keeping cattle, establishing families, and the like (Mbiti 1970:133). If this is the case, it then means that the moral judgments employed in life, apply in the after death. Those who die of immoral acts such as HIV/AIDS, within this construction, cannot enter into the spiritual world. Death from HIV/AIDS symbolizes a permanent exit from the world of the living because it represents an end in itself.

Death from HIV/AIDS is experienced by both the living and the dying as a 'bad' and a perpetual death which does not resonate well with the open/closed duality thought in relation to life and death in many African communities. For example, among the Abagusii good death produces the all important ancestors who will protect the society and ensure continuity of the lineage. Bad death, however, closes this. This open/closed duality thought in relation to life and death influences individual actions towards HIV/AIDS.

In most communities in Sub-Saharan Africa, there are limited studies on death especially outside the realms of fiction and theology. This is because death is not considered as a legitimate field of study. However, with increasing incidences of HIV/AIDS, death from AIDS is now a common risk and a familiar event in most communities in Sub Saharan Africa. Thus there is need to understand how those diagnosed with HIV and the society at large understand and deal with this kind of death and how it influences their actions towards HIV/AIDS prevention.

**Statement of the problem**

In the discourse of HIV/AIDS prevention strategies, death is always taken as a definite risk for non-adherence to preventive strategies. However, how people make sense of this risk is rarely taken into account in intervention programmes. Yet, Illich (1976) who has examined the historical evolution of the social meanings of death in the West argues that within each society, " the dominant image of death determines the prevalent concept of health, and the history of death represents the history of medicalization of the struggle against death in time and space"(Illich,1976:179).Therefore, following the medicalization of death, death now means different things to different people, and the definition of death is now largely a matter of moral judgment rather than a biological fact. This therefore catapults the impetus for understanding the social-cultural meanings and definitions of death from HIV/AIDS in relation to preventive actions in a particular cultural context.

According to Elias (1993), the social meanings of death can be located within the historically developed orientations that people have adopted towards their bodies. To Elias, societies like individuals have unique ways of coming to terms with and dealing with death. In this regard, it is the contention of this study that people in different cultural contexts use different perspectives to make sense of death from HIV/AIDS, which in turn influences how they respond to risk avoidance strategies.

In non-western communities such as the Gusii, the individual is enmeshed in the collective. This is contrary to the Western societies' understanding of personhood which emphasizes on individualism and boundaries. This means that in non-western communities, risk such as death is not experienced, anticipated and countered in relation to a single person, but to a network of social relations. This means that death from HIV/AIDS is not individualized as depicted in HIV/AIDS intervention campaigns. For example, if one member in a social network contracts and dies from HIV/AIDS, other members suffer the social stigma of the disease through association. Due to this, individuals in a social network will evaluate the HIV/AIDS risk differently. Such an evaluation will emphasize different threats associated with HIV/AIDS risk such as threatened social relationships than death; and adopt counter measures aimed at meeting

socially and culturally prescribed attributes of personhood. The emphasized risk and adopted counter measures, however, may or may not resonate with the risk of death as captured in HIV/AIDS intervention programmes.

Further, in trying to make sense of the socio-cultural meanings of death, it is important to note that there are expectations on a person's life (Giddens, 1990). The meaningfulness or the meaninglessness of death thus depends on two evaluations: the individual's self assessment of his/her lived life, and the societal assessment of the dying person. But the two views are not discrete, because social parameters of self-evaluation are determined by the collectivity, and the collectivity is produced socially. Thus, the two are different expressions of the same view because individual views are drawn from the wider social discourse of death. This means that, although dying is an individual process, dying is evaluated in relation to different ideologies, structures and social norms as contained in a particular cultural context. Consequently this study focused on the emic understanding of the socio-cultural meaning of death from HIV/AIDS among the Abagusii-Kenya and its influence on HIV/AIDS prevention

**Objectives the Study**

The main objective of this study was to investigate the social-cultural meaning of death from HIV/AIDS among the Abagusii in Kenya and its influence on HIV/AIDS prevention. Using the interpretative phenomenological analysis theory, the study looked at the socio-cultural meanings of death from HIV/AIDS, the lived experiences of dying from HIV/AIDS and how these lived experiences influenced action towards the prevention of the illness.

**Research questions**

The study sought to answer the following questions:

1. What are the socio-cultural meanings of death from HIV/AIDS?
2. What are lived experiences of people dying from HIV/AIDS?
3. How do these lived experiences of dying and death from HIV/AIDS influence action towards HIV/AIDS?

**Justification of the study**

A number of factors have created an impetus for investigating the socio-cultural meaning of death from HIV/AIDS among Abagusii-Kenya and its influence on HIV/AIDS prevention. These factors include: First, among the Abagusii, public discussions about HIV/AIDS death is limited. This limitation is brought about by public silence which characterizes such deaths (Masese, 2011). However in recent times, due to the high incidences of HIV/AIDS deaths in the community, a musician by the name Man Pepe Sagero in his 2011 song titled "*Omosiki N'eriogo*[1]''(music is medicine), highlighted the importance of one's preparation for his/her death by living to the expectations of the community. In his song, the artist castigates sexual immorality which leads to "bad death" from HIV/AIDS. The consequence of such deaths according to the artist does not only affect the individual but other social network members through stigma. Although the song is aimed at encouraging sexual behaviour change, it brings forth the social meanings and definition of death from HIV/AIDS. In response to this, the study aimed at interrogating whether such social-cultural meanings of death from HIV/AIDS have any implications on prevention strategies.

Secondly, in the recent past there is a growing tendency for death and funeral announcements in the print media to include references to the circumstances of the death. It is now fashionable to see explanations such as an individual "died from a tragic road accident" or following a "long or short illness bravely borne." What is of particular interest here is why the bereaved develop interest in accounting for their deceased. Could these explanations be reactions to the natural culture of managing HIV/AIDS through fear, denial and concealment even in the era of HIV treatment? To unravel this, this study becomes paramount.

Thirdly, most studies on HIV/AIDS intervention programmes especially those focusing on heterosexual transmission have most often focused on social meanings of sex and sexual practices in different cultural contexts. Thus, there are limited studies (if any) focusing on the social-cultural meanings of death and HIV/AIDS prevention strategies.

[1] Bonyakoni Kirwanda Band has a large following among the Abagusii because it promotes contemporary issues affecting the community through songs The song is available at: https://www.youtube.com/watch?v=apbgRxJj9tY Accessed on 1st November 2015

Yet in most communities in Sub-Saharan Africa, sexuality and death are mere opposites of the same coin. For example, sexuality confers to an individual's social identity and status during an individual's life time, and death does so beyond the life time. Therefore, given the fact that most studies which have focused on sexuality and HIV/AIDS intervention programmes have found that people respond to HIV/AIDS prevention strategies in relation to their cultural construction of sexuality, there is need to focus on the socio-cultural meanings of death so as to determine if this has any influence on peoples' actions towards HIV/AIDS prevention strategies.

**Definition of concepts**

**Culture**

These are the sum total of attitudes, customs and beliefs that distinguishes one group of people from another and it acts as an organizational catalyst of everyday life which every member must ascribe to.

***Discourse***

This study will adapt Burr's (2003:6) definition of discourse, as "a set of meanings, metaphors, representations and statements which produce a particular version of an event.

**Dying from HIV/AIDS**

As per the study, these are the experiences of people living with HIV/AIDS in everyday life.

**Ethnicity**

This is a group of people who share a common geographical boundary and distinctive culture, language and lineage.

**Identity**

This is an individual self-conception and self-perception of belonging to a social group with a distinct culture. This is achieved through meeting the cultural expectations of a particular gender in time and space.

**Lived experiences**

These are the experiences that present to the individual as what is real in everyday life in a particular socio-cultural context. These experiences consist of commonsensical realities that are taken for granted and tend to be less accessible.

**Prevention of HIV/AIDS**

In this study, HIV/AIDS prevention will refer to various ways which people use to protect themselves from the threats or risk of HIV/AIDS illness.

**Summary and Organization of the Thesis**

The focus of this study was on the socio-cultural meaning of death from HIV/AIDS and its influence on HIV/AIDS prevention among the Abagusii-Kenya. The impetus for this study was necessitated by the fact that HIV/AIDS remains one of the major causes of mortality in many communities in Kenya as evidenced by various scholarly literature and surveys such as the Annual sentinel surveillance, Kenya Demographic Health survey and the Kenya AIDS indicator survey. Further, in HIV/AIDS prevention discourses, death remains a major risk. As a consequence, death from HIV/AIDS is increasingly common in Kenya. However, the ways in which people diagnosed with HIV/AIDS and society generally make sense of this kind of death and how it influences prevention strategies has been little investigated. Instead, most studies on HIV/AIDS risk reduction have tended to focus on factors influencing sexual practices in various contexts.

Unlike other incurable diseases, HIV/AIDS is an emotive, moralized and socially stigmatized condition which is mostly transmitted through unprotected sexual contact. This moralization of the syndrome inevitably influences health seeking behaviour. In Kenya, there are numerous sources of information which give knowledge on how to

manage the disease for those who have been infected. Most of these sources mostly deal with biomedical management of the disease with no regard to the local people belief systems which influence the health seeking behaviour for those people infected or affected by the disease in most communities.

As noted by social constructionists, people are not mere consumers of information given to them. Instead they synthesize such information into a common shared knowledge as it exists in their institutions, their everyday language and their shared meanings and understanding. This common shared knowledge is constructed through socialization as a result of social interaction, negotiation and power.

This means that people will construct their own realities on how to deal with HIV/AIDS infection based on their cultural belief system and prevailing social and economic circumstances. These constructed realities which may or may not be accurate translations of biomedical management of the disease will nevertheless guide peoples' actions. Therefore this thesis argues that efforts at behaviour change that do not take cognizance of these beliefs are bound to fail in reducing HIV/AIDS transmission in any given community.

In investigating the socio-cultural meaning of death from HIV/AIDS and its influence on HIV prevention, this study was guided by the interpretative phenomenological analysis theory and three research questions which were: what is the socio-cultural meaning of death from HIV/AIDS, what are lived experiences of dying and death from HIV/AIDS and how do these lived experiences of dying from HIV/AIDS influence action towards prevention strategies such as abstinence, being faithful and condom use (ABC). In answering these research questions, data was collected for fifteen months from people who had been diagnosed with HIV, lay persons and opinion leaders such as religious leaders from the Abagusii community in Kenya. The study found that the way people “make sense” of death is dependent on the dominant belief system and the specific socio-cultural meanings attached to particular forms of death.

Among the Abagusii, just like most communities in Sub-Saharan Africa, HIV/AIDS is transmitted through heterosexual relationships. This has made the disease to become a metaphor for moral contamination. People who are infected with HIV/AIDS acquire a spoilt identity and have to shoulder the burden of infection. Therefore an HIV positive diagnosis was noted to make an individual either to engage in a HIV infection transmitting behaviour or a responsible behaviour depending on how one makes sense of the impending death from HIV/AIDS and the presumed life after death as contained in the cultural belief system.

Among the Abagusii, there is a common shared belief that physical mortality does not necessarily lead to spiritual mortality. Immortality of life is assumed to be perpetuated through the process of social reproduction. However, this process is threatened by HIV/AIDS because it is mostly transmitted sexually and yet sexuality is inextricably intertwined with social reproduction. This makes death from HIV/AIDS to be problematic because it threatens the cultural belief of life after death.

Among the Abagusii, death from HIV/AIDS is construed as "permanent death." Therefore those diagnosed with HIV are forced to use various tactics such as getting married and having children (womanhood or fatherhood) in order to conceal their HIV seropositive status. As found in this study, the expectations of social reproduction is more acute among those who are HIV/AIDS positive because the stigma associated with HIV/AIDS is closely tied with the widespread perception of social and moral crisis (a metaphor for HIV/AIDS). Therefore for those people who are HIV positive, to marry (or get married) and have children offers them not only the opportunity to lead normal lives, but also a means to mitigate the stigma associated with the disease.

The pursuit of social reproduction as a strategy of redeeming a spoilt identity was found to be aided by the Antiretroviral Therapy (ART) treatment which is fairly accessible to most HIV positive patients in Kenya. As noted, ART has led to improved health of HIV positive people. This has enabled them to pursue their individual aspirations and community ascribed goals such as social reproduction, because HIV/AIDS is no longer

seen as a certain death sentence. However, in pursuit of social reproduction goals individuals were found to face numerous social, ethical and medical dilemmas as they tried to live their ambitions and living up to the social norm. For example, HIV positive patients are medically advised that unprotected sex is risky yet socially it is seen as a marker of trust and expression of the possibility that the relationship could evolve into marital union with children.

As a consequence, this study found out that these dilemmas negatively affected HIV/AIDS prevention strategies of abstinence, being faithful and condom use (ABC). This was complicated by the perception that HIV/AIDS itself is a symbol of social crisis and moral decline. For example, HIV positive patients found it extremely hard to discuss about safe sex practices with their sexual partners for fear of disclosing their HIV seropositive status.

Although dying from HIV/AIDS was mostly an individual social problem, death from HIV/AIDS was equally problematic to immediate kinship members. This was because of the stigma of having a close kin dying from HIV/AIDS and the construction of such deaths as "bad death." As observed in this study, people who died a "bad death" were assumed not to have life after death, thus they attracted little public sympathy and material support for a "decent" funeral.

In light of the above, bereaved families were pressured to conceal the cause of death of their kin by using various tactics. Some of these tactics include, blaming such deaths on witchcraft and consequently using vigilante group members such as "*sungusungu*" to banish those blamed for it. Others emphasized the immediate cause of death which in most cases was assumed not to be related to HIV/AIDS illness. In some cases, the family turned mourning activities into life celebrations of the deceased through lavish feastings where positive achievements attained by the deceased during his/her lifetime were the only ones being emphasized through newspaper obituary advertisements and eulogies.

The management of HIV/AIDS death through the culture of denial and concealment was largely a reaction of fear of social stigma, ostracism and isolation which are predominant societal responses to those diagnosed with HIV/AIDS. This culture is further reinforced by the dominant cultural belief system and lay persons discourses that promote the idea that people with HIV/AIDS do not experience life after death. As a result, those who are diagnosed with HIV/AIDS are thereby pressured into behaving as though they are not infected in an attempt to conceal their HIV seropositive status. The inability of such persons to negotiate safe sex pressures them into having unprotected sex, consequently increasing HIV transmission.

In conclusion, this thesis argues that for HIV/AIDS prevention strategies to be effective there is need to incorporate cultural beliefs associated with death from a particular illness. These cultural beliefs play a big role in influencing people's health seeking behaviour. This is because in most communities, death is not perceived as an end of life but as a transition to another life. This transition which bestows to an individual high status and proper identity is dependent on the construction of one's individual death. Therefore people who are faced with impending death from HIV/AIDS may engage in behaviours which may either aid or prevent the spread of the disease depending on how they make sense of such a death in their socio-cultural context.

This thesis is divided into two parts. **Part one** covers chapter one - chapter four. In **Chapter one**, I provide a theoretical and empirical grounding of the study by using various theoretical approaches which have guided social scientists' research on HIV/AIDS since its advent. In doing so, the chapter argues that the problem of managing HIV/AIDS relies on the social construction of HIV/AIDS as an illness in a particular cultural belief system and not HIV/AIDS as a disease or a biomedical syndrome. The chapter further discusses theories of death and dying to illuminate the socio-cultural meanings of dying from HIV/AIDS and its influence on its management.

**Chapter two** critically discusses HIV/AIDS as a major social problem in Kenya. Using illness narratives of people living with HIV/AIDS, the chapter argues that the major

social problem of HIV/AIDS in any community is the social disruption of social life. This is evidenced by the impact of the illness on the existential life project of those infected where it imposes several social life limitations. These limitations compel those infected to calibrate a new life story, new values and new life plans which in turn influence how they manage the illness in their everyday lives.

**Chapter three** provides the background information on the Abagusii. In particular, the chapter discusses their land, social organization and conception of life and death. The chapter underscores the fact that the Abagusii way of life especially on issues of life and death are greatly influenced by the values and knowledge as found in their cultural belief system. This chapter therefore lays ground for understanding different constructions of people as shaped by culture and society and how they shape individual understanding of life and death. This understanding is important because it is the contention of this thesis that risk and risk-reducing interventions like in the case of HIV/AIDS are shaped by culture, society and history.

**Chapter four** explores the methodological processes, theories and practice that guided this study. The chapter in particular discusses how the interpretative phenomenological analysis theoretical framework informed methodological choices and decisions made in the course of the study. The chapter also discusses the approaches and methods used in the study which included: case study approach, sample selection and sample size, snowball sampling technique, use of in-depth conversational interviews, focused interviews, tape recording of interviews and field notes. Further, the chapter discusses the challenges of maintaining a critical distance as an emic anthropological researcher researching on a sensitive topic of death and HIV/AIDS illness.

**Part two** covers chapter five **to** chapter seven which draws the arguments to conclusions. In **Chapter five,** death from HIV/AIDS and its moral reconstruction is examined. The chapter argues that death from HIV/AIDS is experienced as "bad death" which not only disrupts social life and kinship relations but also traditionally established practices of dealing with the dying and the dead as contained in the cultural belief system which

emphasizes on life after death. Due to this, there are new evolving practices of dealing with death from HIV/AIDS which is characterized by the culture of concealment, silence and denial. This chapter therefore argues that death from HIV/AIDS is producing new socio-cultural meanings of death which necessitates new strategies of managing dying and death.

**Chapter six** critically examines the interplay between the socio-cultural meanings of death from HIV/AIDS and adoption of prevention strategies namely: abstinence, being faithful, and condom use in people's daily life experiences. In particular the chapter critically discusses how individuals facing impending death from HIV/AIDS negotiate safe sex and social reproduction issues especially on parenthood (fatherhood and motherhood) which are key to "good death" as emphasized by the cultural belief system.

**Chapter seven** critically discusses and interprets key results of the study based on interpretative phenomenological analysis theoretical framework which guided this study. In this case, the socio-cultural meanings of death from HIV/AIDS are discussed and interpreted in relation to how they inform action towards HIV/AIDS prevention. The chapter then summarizes the key findings.

# CHAPTER ONE
# THE SOCIAL CONSTRUCTION OF DEATH FROM HIV/AIDS

## Introduction

This chapter discusses the social construction of HIV/AIDS in Kenya and its implication on intervention strategies. In underscoring this, the chapter examines various theoretical frameworks which have informed HIV/AIDS intervention strategies since its advent. The chapter further discusses the social meanings of death from HIV/AIDS and the specific ways in which such death problematizes the management of HIV/AIDS by locating such death within the wider socio-cultural environment.

## Social meanings of HIV/AIDS and prevention

The first case of HIV/AIDS in Kenya was reported in 1984. Immediately after this official reporting, there was denial and skepticism by government officials, religious and community leaders (Ogot, 2004). This response was not only unique to Kenya but among many countries in Africa. This initial response is argued to have laid ground for the rapid spread of the disease.

In Kenya, the government's initial inaction towards the disease was influenced by the prevailing political and economic factors. According to Okuro (2007), Kenya, like many other countries was facing an economic crisis at the advent of HIV/AIDS due to the effects of the 1970s oil debacle, diminishing returns from agricultural exports such as coffee and tea due to liberalization of the economy and the increasing debt. Among the citizenry, this period was characterized by declining living standards, escalating poverty and inadequate provision of social welfare services such as health care and education. All these presented a challenge to the country's development and response to the new epidemic.

In response to these economic challenges, the Breton wood institutions (World Bank and International Monetary Fund) recommended a series of macro-economic measures. These recommendations became conditionality for continued donor support. These

recommendations demanded *inter alia*, limiting budget deficit and cutting down on social spending in areas such as health and education, financial liberalization, privatization of state owned enterprises and change of governance structure by adopting a multi party democracy (Whiteside, 2002).

These policies were, however, construed as undermining the legitimacy of the government among the political class. This construction was given credence by the Breton Wood institutions' demand for change in governance structure, tightening of financial expenditure by reduction of state employees and privatization of state owned enterprises which in most cases served the ends of political clientele (Chabal, 2005).

Among the citizenry, the Structural Adjustment Programs (SAPs) recommended by the Breton Wood institutions had profound social and economic consequences particularly in rural areas. With reduction on expenditure of social welfare services such as health and education, most people were unable to access such services. This pushed many of them to the margins of vulnerability through adopting survival mechanisms which put them into risk of HIV/AIDS infection (Craddock, 2004).

With dwindling revenue from agricultural exports due to liberalization and reduction of foreign exchange, the Kenyan government had to protect the tourism industry which was the only source of foreign exchange from bad publicity over existence of HIV/AIDS in the country. In this regard, the government had to do everything possible to control information about existence of HIV/AIDS as a way of protecting the industry. In 1986, for example, the government banned the *International Herald Tribune* that reported the first case of HIV/AIDS in the country[2]. This was followed by a racial war between Kenya and Britain over AIDS related mythologies. All AIDS reports in the Western countries' media about its existence in Kenya were thus seen as a "smear campaign" to cripple the tourism industry and scare away foreign investors (Okuro, 2007).

[2] Kenya Times (1987): "British media vultures hover over Kenya". Kenya Times February 7th 1987

Despite the government's depiction of HIV/AIDS existence as an economic sabotage by western countries, it however advised its citizens to avoid sexual immorality as the only way of preventing the spread of HIV/AIDS. The government stand on sexual immorality was supported by mainstream churches but was more hinged on dealing with the negative influence of tourism on people's sexual behaviour. According to mainstream churches, sexual vices such as homosexuality and sexual immorality which were associated with tourism were the main causes of HIV/AIDS. Therefore to deal with HIV/AIDS, the government had to look at the tourism industry afresh. This moralist stand by both the government and mainstream churches made HIV/AIDS a disease of people who were sexually immoral and those with queer sexual orientations (Ogot, 2004).

However, it's important to observe that towards the early 1990s, the government's position slowly but systematically shifted to embrace a rather proactive approach to the fight against HIV/AIDS. This shift was occasioned by a number of factors. First, towards the end of 1980s, the number of those infected with HIV had increased substantially to the extent that the minister for health warned that if appropriate measures were not taken to curb the spread of the disease, the number of HIV/AIDS patients would be frightening.

Second, the pressure emanating from a number of Non Government Organizations (NGOs) which were dealing with HIV/AIDS key amongst them, Kenya AIDS NGOs Consortium (KANCO). KANCO was formed in 1990 by a group of NGOs and religious organizations with the main objective of networking in the fight against HIV/AIDS. These NGOs pressurized the government to be proactive about HIV/AIDS issues.

Third, was the pressure from Kenya's key development partners such as the World Health Organization (WHO), United Nations Development Programme (UNDP) and the World Bank. These organizations demanded that the government admit the presence of HIV/AIDS in Kenya and have control of HIV/AIDS as a national priority. They also instructed the government to mobilize all resources at its disposal to create awareness of the disease to the people.

As a consequence, the government in 1987 developed and launched the First Comprehensive Five-Year Medium Term Plan (MTP). The plan focused on the prevention of HIV/AIDS infection by screening blood, promoting safer sex practices and early diagnosis of sexually transmitted diseases (STD). In the period 1992-1996, the government developed a second MTP to mobilize other sectors including NGOs and the private sector in the fight against HIV/AIDS. Between 1997- 2000, the government recognized HIV/AIDS as a serious economic development and demographic problem which needed an urgent mitigation action. As a result, HIV/AIDS became part of the government's development policy issue. From the year 2001, the government developed policies aimed at improving accessibility to treatment to those infected by HIV/AIDS (Masese, 2011).

The government's initial inaction and conflicting position about HIV/AIDS' presence in the country witnessed the stigmatization of HIV/AIDS victims and gave room for speculation and escalation of lay discourses about the disease. All these weakened the fight against the disease. For example, when HIV/AIDS was first reported, it was associated with prostitutes and homosexuals. This association reinforced and legitimized stigmatization and discrimination of those people who were infected (Kopelman, 2002). This was made worse because of the unpredictable government position.

Given the fact that throughout history, the perception of an epidemic and pandemic has been a matter of power and authority (Moulin, 1991; Moulin *et al* 2010; Moulin, 2009; Slack, 1992), in Kenya, the disease was demonized by the Government. For example, in 1989 the president directed the Ministry of Health to do statistics on HIV/AIDS patients so as to identify the number of Kenyans and outsiders suffering from the disease. He further ordered the isolation of the infected patients to avoid the spread. On the other hand, the religious leaders insisted that HIV/AIDS was a sin and for those who are sinful (adulterous or immoral people) in nature. Consequently, the church showed no interest in people living with HIV/AIDS and spoke about it as a disease of "others"[3]. In rural areas,

[3] See Daily Nation 17th March 2006.

HIV/AIDS was seen as a disease for those living in towns and sexual deviants such as prostitutes.

Those who held some power and authority at the local level also espoused their own meanings and interpretations of the disease. Though these interpretations were variant with biomedical explanations, they nevertheless determined the local people's response and perception of the disease (Horton and Aggleton, 1989; Treichler, 1999; Farmer, 1992). Among the Abagusii, for example, HIV/AIDS was believed to be caused by non observance of sexual taboos. This caused those infected with HIV/AIDS to be stigmatized and discriminated.

Stigmatization and discrimination of people infected with HIV/AIDS did not emanate from the government alone but also from other institutions of the society. For example, the church doctrines regarding sexual behaviour helped to create a perception that those infected had sinned and thus deserved the punishment. At the family level, stigma and discrimination was manifested in the form of blame and rejection because it was associated with promiscuity and homosexuality.

This kind of environment was unsupportive to many intervention strategies for fighting HIV/AIDS. For example, men feared not only testing for HIV but also revealing their status because it would be assumed that they were homosexuals. Similarly, women feared revealing their status because they would be labeled promiscuous. All these caused HIV seropositive persons to isolate themselves for fear of being stigmatized and discriminated.

The extent to which HIV/AIDS campaigns never worked in Kenya is observed by Kwamboka Oyaro:

> *……may be the problem has to do with the very first messages that were crafted when the first HIV/AIDS case was diagnosed. In those days, posters depicted people with the disease as thin, bony and dying creatures…..the pictures were meant to instill fear and the underlying*

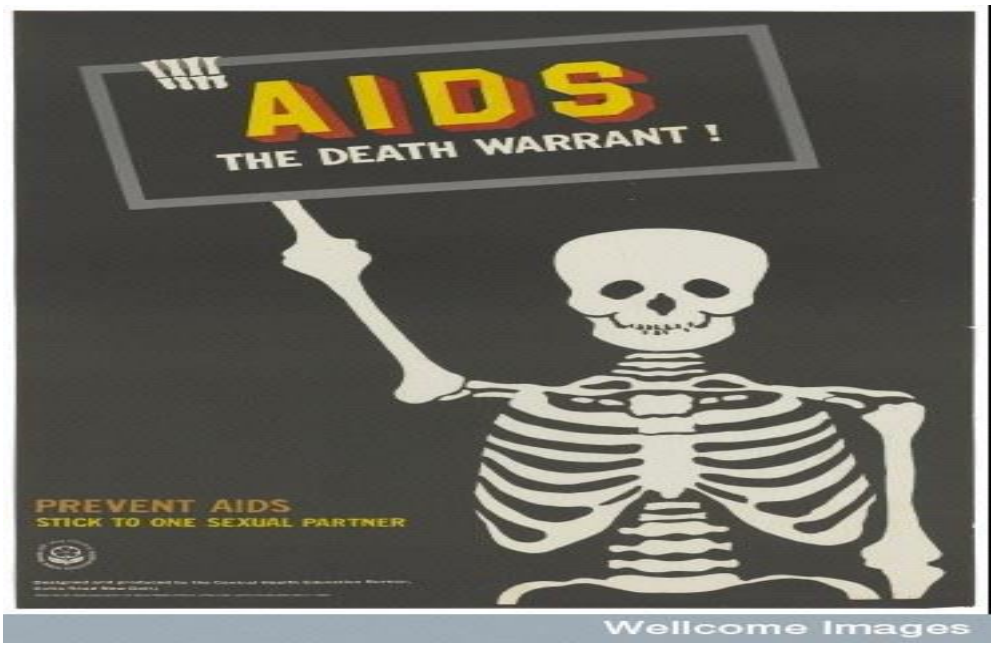
*message was one of blame: you will contract HIV if you engage in promiscuous behaviour.*[4]

The initial response to HIV/AIDS created a host of meanings about the disease which in turn influenced intervention strategies. In Kenya the disease was associated with certain risky groups such as prostitutes, drug addicts and homosexuals. As a consequence, intervention strategies which were spearheaded by medical professionals focused on understanding the behaviour correlates of these risky groups. It was assumed that understanding these groups would enable medical personnel to intervene effectively in mitigating the impact of the disease.

The focus on intervention strategies for risky groups structured the understanding of HIV/AIDS in a marked manner. It made the disease to be perceived as a disease of "others'' resulting to the naming and blaming pattern of disease attribution (Kopelman, 2002). This created a sense of security among those who did not fall under the construction of "other". As a consequence powerful linguistic metaphors such as "killer disease" and "gay plague" were mobilized around HIV/AIDS which reinforced stigmatization and discrimination. Given the fact that HIV/AIDS is predominantly transmitted through sexual intercourse, it was construed as a punishment for those who were sexually immoral (Sontag, 1998). This made those who were infected to experience shame and isolation which in turn affected their sense of self. At the same time it made death from HIV/AIDS to be stigmatized (**see Figure 1.1**).

[4] Daily Nation September 2003

**Figure 1.1: HIV/AIDS poster**




The use of powerful linguistic metaphors in HIV/AIDS intervention strategies was counter-productive. Instead of creating awareness and encouraging behavior change, it led to the culture of fear, shock, silence, blame and condemnation. All these alienated those who were living with HIV, exposing them to ridicule and social stigma. This approach was nevertheless found to be ineffective in mitigating the impact of HIV/AIDS because even those people who were not in the risky groups were found to be infected. This shifted HIV/AIDS intervention strategies from focusing on risky groups to risky behaviours.

In this regard, most intervention strategies started focusing on risky behaviour and changing knowledge, attitudes and beliefs about sexuality that might be associated with risk of HIV/AIDS infection (Parker, 2001). Based on Health belief models, these strategies aimed at empowering people with information about HIV/AIDS and how to protect themselves from infection. It was assumed that once people are empowered with information about the severity of HIV/AIDS and how to avoid infection, they will make a rational health behaviour decision (Hart *et al* 1992). As a result most intervention strategies focused on promotion of safe sex practices (**see figure 1. 2**).

**Figure 1.2: Poster on safe sex practices**




The promotion of safe sex practices was universally done with no regard to diverse social and cultural factors governing sexuality. As a consequence, HIV/AIDS was individualized as a disease of lifestyle and choice (Alcorn, 1988). In this regard, an individual was assumed to have power of protecting him/herself from HIV/AIDS risk using the known safe sex practices (abstinence, being faithful and condom use) regardless of the socio-cultural factors influencing sexuality. This individualized the risk of HIV/AIDS and assumed that individuals have a rational control over their sexual behaviour regardless of their socio-cultural contexts.

The individualization of HIV/AIDS risk and de-contextualization of the epidemic and sexuality was due to the fact that these intervention strategies were greatly influenced by medical discourses. As a result of this, it enhanced stigmatization of those infected with HIV/AIDS through blame attribution of the disease.

The use of information empowerment and promotion of safe sex practices as a strategy of mitigating the impact of HIV/AIDS was, however, found to be ineffective. Instead, the structure of risk in every society was found to be mediated by social, economic and structural factors and not information/knowledge alone (Schoepf, 2004). As a consequence, focus on HIV/AIDS prevention intervention strategies shifted from

information/knowledge empowerment to interpretation of cultural meanings as important in understanding sexual transmission of HIV/AIDS in various cultural settings. Findings from these researches on interpretation of cultural meanings identified cultural factors which are important in making HIV/AIDS prevention intervention strategies in specific contexts effective (Treichler, 1999).

In addition, other approaches focused on social representations and cultural meanings that shape the construction of sexual experiences in diverse cultural contexts. These approaches were influenced by the social constructionist approach and aimed at understanding the inter-subjective cultural meanings related to sexuality (Parker, 2001). Through ethnographic research on the socio-cultural construction of sexual experiences, it was found that the inter-subjective meanings were not only influenced by cultural factors but also by structural, political and economic factors.

Consequently, efforts to mitigate the impact of HIV/AIDS started focusing on the role of structural factors on prevention intervention strategies. This focus brought forth how diverse cultural, political and economic processes and policies create the dynamics of epidemics and the impact on intervention programmes (Farmer *et al* 1996; Porter, 1997). Through this understanding, culturally sensitive and culturally appropriate community based HIV/AIDS prevention programs were developed for diverse contexts.

Apart from focusing on how structural factors shape sexual experiences and HIV/AIDS vulnerability, other studies focused on how societies structure sexual interactions between social actors. In essence, these studies focused on how societies define sexual partners and practices, the rules, regulations, norms and taboos governing sexual behaviour and the culturally expected outcomes of sexual interactions (McGrath *et al* 1993). It was found that sexual behaviour is governed by implicit and explicit rules and regulations imposed by sexual cultures of specific communities and gender power relationships in various cultures. This awareness necessitated HIV/AIDS prevention strategies to start incorporating gender power relationships (Farmer *et al* 1996; Gupta *et al* 1996; Ward, 1991).

As noted from the above discourse on HIV/AIDS prevention, most of the prevention intervention strategies have focused on sexuality. This is important because HIV/AIDS has brought forth an added significance on the pathways that lie at the heart of social reproduction. According to Setel (1999), social reproduction is the process by which people in a particular community perpetuate themselves and their identities from generation to generation. However, this process is threatened by HIV/AIDS risk which is death. As a consequence, it is the contention of this thesis that understanding how people construct death in their everyday life will augment prevention intervention strategies given the fact the HIV/AIDS has no cure yet.

**Social construction of death and dying from HIV/AIDS in Kenya**

Since the advent of HIV/AIDS, we see death happening almost daily. Death has become a common phenomenon. There are deaths reported, either from short illnesses, long illnesses, from accidents, natural and manmade epidemics, etc. Somehow, death has become part of us, not like in the past when it could take a long time before you hear that someone has died.

Normally, death is seen as a natural and biological phenomenon. This is because people fall sick, and their bodies are weakened due to the illness, they go to hospital, are treated and some become well while others die. Death is therefore associated with disease, the cessation of bodily functions and with gradual biological deterioration of the human body. Death is indeed a natural phenomenon, in the sense that it is embedded in the human body from the beginning of life and because it is a necessity that humans, as everything else, die. In many societies, death is a dreadful and an unpleasant event which represents the absolute end of a person (Elias 1993).

Death is also seen as a social and cultural phenomenon. This is because it is firmly embedded within, shaped by and constructed in concrete historical, social and cultural contexts. As the 'father' of deconstruction, Jacques Derrida (1967) observed that everything is a matter of human interpretation and context. Illich (1976) who examined the historical evolution of the social meanings of death in the West argues that within

each society, the dominant image of death determines the prevalent concept of health, and that the history of death represents the history of the medicalization of the struggle against death in time and space (Illich 1976). Illich succeeds in showing that following the medicalization of death, death now means different things to different people (Feifel, 1965), and the definition of death is now largely a matter of moral judgment rather than a biological fact (Veatch, 1989).

With no cure yet, HIV/AIDS as a disease seems to have undermined man's victory over disease. Through the development of modern biomedicine, the search for help against danger and death has shifted from supernatural systems of belief to secular belief systems (Elias, 1993). Life in modern societies has become more predictable while demanding from each individual a higher degree of foresight and control of passions, Elias (1993). This explains why there is a relatively high life expectancy in the Western societies due to increased security against death as people are now well cushioned against threats of hunger, war or violence by the state or advanced technology (Elias, 1993).

Like Illich (1976), Elias (1993) locates the social meanings of death within the state of civilization of each society or group. Elias (1993) locates the social meanings of death within the stage of civilization of each society. In less developed societies where a high degree of insecurity still exists, where medical knowledge and technology is still not well developed, where hunger and starvation is still a common feature, where the state organs are still weak to guarantee individual safety, the uncertainty that follows makes death less predictable. In these societies, the attachment to other worldly beliefs that promise metaphysical protection from the blows of fate are high because man is not sufficiently in control of events. Thus attitudes to dying, and the dominant representation of death in any society cannot be understood completely without reference to the security and predictability of individual life and the correspondingly increased life expectancy (Elias, 1993).

Byock (2002) argues that death profoundly impacts our understanding and experience of meaning in life. Although it remains unknowable, death’s relationship to life is essential

and as profound as the relationship of darkness to light. Inquiry into the meaning and value of death can be approached from cultural, individual, and communal perspectives. Berger (1967) argued that humans are a species whose very conditions of embodiment force them to act, and to invest themselves and their actions with meanings in order to survive. To him, death is therefore experienced as a threat to this investment and has to be dealt with through a shared belief system such as religion. This approach is appropriate in dealing with death in simple societies, but not in plural societies like Kenya where traits of modernity co-exist with traits of simpler societies.

Giddens (1990) argues that responses to death are shaped by the high modernity culture which is associated with modern societies. Giddens' approach however, does not seem to be specific to Western societies where capitalism and secularism have replaced communal shared belief systems. In these societies, the individual is left to make sense of death in private and to devise ways of coping and dealing with death. Giddens therefore suggests that there is a tendency for modern people to become increasingly associated with their bodies, and the prospect of death poses specific existential problems for these people in high modernity (Giddens 1990, 1991), but like Berger, his approach is too generalized.

On the other hand, Elias (1993) locates the social meanings of death within the historically developed orientations that people have adopted towards their bodies. To Elias, societies like individuals have unique ways of coming to terms with and dealing with death. In this case modernity in the West enables people to see and evaluate the individual as an entity, while in Kenya; the individual is enmeshed in the collective so that it is difficult to evaluate the person in isolation from his or her group. If one of its members contracts HIV, the next of kin suffers the social stigma of the disease through association. It is this social contamination from relationship to a person living with HIV which compounds the problem of managing HIV/AIDS in Kenya.

Consequently, in trying to make sense of the socio-cultural meanings of death, it is important to remember that there are expectations on a person's life, Nzioka (1994). The

meaningfulness or meaninglessness of death thus depends on two evaluations; the individual's self assessment of the meanings of his or her lived life, and the societal assessment of the dying person. These two views are not discrete, because social parameters of self evaluation are determined by the collectivity and the collective view is produced socially Nzioka (1994). The two are different expressions of the same view because individual views are drawn from the wider social discourse of death. However as Elias 1993 argues, dying is a very lonely process, although the problem of loneliness of the dying has to be evaluated in relation to the attitudes of the living (Elias 1993).

HIV/AIDS as an illness has no known cure, and has demolished man's barriers against death. Probably, when a cure or vaccine against AIDS is developed, then the present perception of HIV/AIDS may wane. Death from HIV/AIDS being a result of a shameful disease is therefore a bad death. But whether death is good or bad is a social matter (Bradbury, 1993).

Berger (1967) argued that death is dealt with through a shared belief system. In Kenya, the dominant shared belief systems are Christianity, Islam and traditional beliefs. Both Christianity and traditional belief systems seek to enable people to come into terms with death by denying that the demise of the physical body represents a permanent departure. A distinction is drawn between 'ideal' and 'real' death (Veatch, 1989). Realistic death is one in which we have the '*memento mori*, the conqueror worm and other paraphernalia of maggoty', while the idealistic death is where people deny the corporeal nature of the body and strive to deny physical dissolution by substituting it with suggestions of spiritual beginnings (Hoffman,1965). Most people identify themselves with religious beliefs which asseverate that death is not death at all, but is rather a fictive experience and a brief transition between one more important existence to another (Feifel, 1965). Those who subscribe to the secular high modernity culture which shifts the understanding of death from idealistic territory of culture to the realistic sphere of nature are in the minority (Giddens, 1991).

Death through HIV/AIDS is constructed in the dominant beliefs of Christianity and traditionalism as resulting from sinful acts or acts of immorality which in themselves constitute barriers to entry into the life-after-death. Both belief systems adopt a puritan approach to death where 'good' death is one which ensures life after death. Death from or in acts such as robbery and promiscuous sex leads individuals to hell (Elias, 1993), and in traditional belief systems, people who die through such acts cannot join the ancestral world of immortality. Mbiti, 1970 argues that African people see man in two parts: the physical part which at death is put into the grave or otherwise disposed off, and the non-physical part which survives and bears the personality of the individual in the hereafter (Mbiti, 1970). People who die from immoral acts such as HIV/AIDS cannot enter into the spiritual world. Death from AIDS symbolizes a 'permanent' exit from the world of the living because it represents an end in itself. Within this construction, death from HIV/AIDS is experienced by both the living and the dying as a 'bad' and perpetual death. To those dying from HIV/AIDS, even a last minute repentance is no guarantee that God will forgive them and hence no assurance of entrance into the heavenly kingdom which is the promise of life after death. To the living, loss of a loved one through HIV/AIDS is a permanent loss. To the Christians, the dead go to hell and to traditionalists the dead do not go to join the ancestral spirits.

Death from AIDS is a “bad death” because it kills the young. In both modern and traditional societies, specific values are attached to youthfulness. In the west, the desire to remain young has produced an almost neurotic desire to control ageing, and a refusal to accept one's own ageing leading to narcissistic personalities (Lasch, 1991). Modern societies are also so future oriented that the prospect of death presents a major existential problem (Giddens, 1990). The power of death shatters people's ontological sense of security, and brings about a sense of meaninglessness (Giddens, 1990; Shilling, 1993). But death of young people is experienced as a more serious loss because it threatens the future of society. Society may experience the loss of a child as untimely, and the loss of the aged as normal (Feifel, 1965).

Although HIV/AIDS has moved from being a fatal to a chronic illness due to improved treatment, it is seen as a biographical disruption in one's life. As a consequence those diagnosed with the illness try to calibrate new ways of living as they try to meet their community ascribed cultural life expectations. This new existential reorientation problematizes the life of those living with HIV/AIDS and this has profound implications on the management of the illness.

Lastly, death from AIDS threatens to disrupt tradition where funeral arrangements and burials have always been public and communal events. Following the moral panic of AIDS, there are well entrenched fears of contagion and social contamination. The moral panic surrounding AIDS means that the community is less likely to perform death rituals which are crucial in the transition of the dead to the world of ancestors. As a consequence new methods of managing HIV/AIDS death through silence and concealment have emerged among the deceased's kin. These new methods of managing HIV/AIDS death have implications on the overall management of HIV/AIDS at the community level.

**Understanding death from HIV/AIDS through Interpretative Phenomenological Analysis (IPA)**

Interpretative Phenomenological Analysis (IPA) has been developed as a distinctive approach to conducting qualitative research. (IPA) is a qualitative approach which aims to provide detailed examinations of personal lived experience. It produces an account of lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions and it recognizes that this is an interpretative endeavor as humans are sense-making organisms. It is explicitly idiographic in its commitment to examining the detailed experience of each case in turn, prior to the move to more general claims

IPA's theoretical underpinnings stem from phenomenology which originated with Husserl's attempts to construct a philosophical science of consciousness, with hermeneutics (the theory of interpretation), and with symbolic-interactionism. IPA is strongly influenced by phenomenology which is a philosophy developed by Husserl and later extended by philosophers such as Heidegger and Gadamar. Husserl's transcendental

phenomenology focuses on the 'life world' of an individual and regards experience as the fundamental source of knowledge (Dowling 2007). It argues that the 'essence' of a phenomenon can be understood by revisiting a person's immediate conscious experience of it prior to any reflections or explanations being imposed. Phenomenology concerns itself with a conscious experience from the subjective or first person point of view. It studies the structure of various types of experiences, ranging from perception, thought, memory, imagination, emotion, desire and volition to bodily awareness, embodied action and social activity. Phenomenology is thus a philosophy of facticity which investigates the world and human existence. It seeks to reflect on the conditions of possibility of experience and cognition and advocates a life-world, insisting that since man is in the world, he only knows himself by means of inhabiting the world.

Phenomenology is thus concerned with the way we experience things and the meanings things have on our experience. The philosophy holds that the subject does not have a monopoly either on itself- understanding or on its understanding of the world, maintaining that these are aspects of the self and of the world that only become accessible and available through the other, Merleau-Ponty (1962). For phenomenologist, subjectivity is embodied in the social historical and natural contexts, so that existence is not simply a question of how the subject apprehends itself, but also how others apprehend it. It investigates the domain of ignored obviousness that impedes the subject's reflection of the world. It is a perpetual meditation, a critical self-reflection that does not take anything for granted. It is concerned with the production of meaning. It defines meaning as the individual signification of experience and interprets experience as a quest for meaning.

Although IPA is clearly influenced by Husserlian phenomenology in its aim of understanding the individual's experience, it does not seek to bracket the researcher's values and beliefs; instead, it views these as necessary in understanding and making sense of the person's experiences (Shaw 2001).

Another influence on IPA is Heidegger's hermeneutic phenomenology seen through the emphasis placed on interpretation and the role of both participant and researcher in a dynamic research process. Unlike Husserl, Heidegger emphasized that there is always an element of personal engagement that arises from being 'thrown into the world', where some events, objects and experiences have more meaning and purpose than others, and that these form the basis for interpreting and making sense of our experiences (Wilding and Whiteford 2005).

IPA acknowledges that it is not possible to have direct access into someone's 'life world' because this is influenced by the researcher's own experiences, values and pre-understandings, which are considered necessary in interpreting and making sense of an individual's experiences. Smith and Osborn (2008, p53) referred to this dual process as a double hermeneutic, whereby 'the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world'. It is this emphasis on interpretation that moves the IPA researcher away from simply describing the individual's experience towards an understanding of the phenomenon that is context specific and inclusive of both the individual and the researcher.

The meanings an individual ascribes to events are of central concern but are only accessible through an interpretative process (Smith, Jarman and Osborn, 1999). Human beings are not passive perceivers of an objective reality, but rather they interpret and understand their world by formulating their own biographical stories into a form that makes sense to them.

IPA is therefore an inductive approach concerned with understanding an individual's personal account of a particular experience or phenomenon, rather than trying to find causal explanations for events or produce objective 'facts' (Smith and Osborn 2008). The aim of IPA is to explore in detail the processes through which participants make sense of their own experiences, by looking at the respondent's account of the processes they have

been through and seeking to utilize an assumed existing universal inclination towards self-reflection (Chapman & Smith, 2002; Smith *et al.*, 1997).

Thus, IPA research has tended to focus on the exploration of participants' experiences, understandings, perceptions and views (Brocki, J and Wearden, A 2006). The participants do self-reflection, and interpret their experiences into some form that is understandable to them. IPA thus explores how people ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman and Osborn, 1999).

For a researcher to understand a particular phenomena affecting people and why they react to it the way they do, he or she has to understand that phenomena from the point of view of the participants. IPA thus offers the researcher the opportunity to develop an idiographic understanding of participants, and what it means to them, within their social reality, to live with a particular condition or be in a particular situation (Bryman, 1988). It thus facilitates an understanding of the complexity of bio-psycho-social phenomena (Boyle, 1991). In IPA, a researcher tries to empathize with the participants' situation as much as possible, but acknowledges that access depends on and is complicated by the researcher's own conceptions required in order to make sense of that other personal world through a process of interpretative activity (Smith, Jarman & Osborn, 1999).

A researcher tries to get close to the participant's personal world or, (to take an insider's perspective according to Conrad's 1987), but this is almost impossible because of the researcher's own conceptions. Therefore, in order for the researcher to understand the personal world of the participant, he/she has to undergo the process of interpretation. Thus, the participants are trying to make sense of their world through interpretation, and the researcher is trying to make sense of the participants trying to make sense of their world, also through interpretation. IPA is therefore suitable for this study because it enables me make meaning of people's understanding about HIV/AIDS death, their experiences of being HIV positive and how these meanings influence their action towards HIV/AIDS prevention.

**Summary and conclusion**

This chapter provides a context for this study and motivates the use of Interpretative Phenomenological Analysis (IPA) theoretical framework. Through review of relevant literature the chapter argues that death from HIV/AIDS is more of a social than a biological fact and has much more implications in the management of HIV/AIDS at this time when it's more of a chronic illness due to advancement on its treatment. Therefore the challenge of making HIV/AIDS prevention strategies effective lies on the understanding of the social and symbolic meaning of death and dying from HIV/AIDS in various cultural contexts.

## CHAPTER TWO

## HIV/AIDS DISEASED BODIES AND SOCIAL DISRUPTION

### Introduction

*What can I say mama X2*
*AIDS is dividing people*
*AIDS has broken my marriage*
*AIDS has divided my family*
*Those who used to eat with me and drink with me*
*Have started to ignore me*
*They say I got the sickness of AIDS*
*All my friends have cut me off*
*Who can I complain to?* (Grand Maitre Franco Luambo - *Attention na sida* 1987)[5]

Health is considered a fundamental human right and a key pillar to any society's social and economic development. However, the illness caused by HIV and its fatal consequences is a major health challenge. With no cure, the high morbidity and mortality rates due to rapid spread of HIV/AIDS in most countries in Sub-Saharan Africa is a major development problem with far reaching consequences beyond the health sector (UNAIDS, 2016; Fortson, 2011).

Conventionally, all diseases which affect mankind have an enormous impact on them. However, the impact of HIV/AIDS differs significantly. This is because the HIV virus attacks the body's immune system making it more vulnerable to opportunistic infections. Even though these opportunistic infections can be managed by antiretroviral therapy, they nevertheless strip an individual's social and economic ability to generate livelihood. This makes the impact of the disease to reverberate far beyond the infected individual (Masese, 2011; Denis *et al* 2006).

[5] Available at: https://www.youtube.com/watch?v=M2dwiZ5pRFU; Accessed on November 24, 2015

Though over time HIV disease has come to be conceptualized as a chronic illness, at individual level the disease is seen as a biographical disruption (Kleinman, 1988; Markotic, 2003; Le Marcis, 2012). As Machado (2012) posits, the trauma of first diagnosis, the lingering prospects of physical deterioration, self blame and shame, isolation and problems with disclosure of HIV status remain constants in the lives of those infected with HIV. These profound difficulties are best understood through existentialist paradigms which illuminate the lived experiences of those weighed down by the reality of HIV infection. In this chapter, I apply the existentialist concept to examine the lived experiences of individuals who have been diagnosed with HIV how they (re)negotiate their disrupted lives.

**Existential disruption and meaninglessness**

Since the advent of HIV/AIDS more than four decades ago, the disease has continued to be construed as an "imminent death sentence". This has made the experience of being diagnosed with the disease a traumatic life event in one's life-project. Consequently, those infected with the disease have come to represent lived bodies suffering existential disruption due to possible limitations imposed by the disease. These limitations compel those infected to calibrate a new life story, a new character or a way of being-in-the world which demands existential reorientation (Kuller and Koltus, 2007; Kleinman, 1988).

Although HIV/AIDS has moved from being a fatal to a chronic illness, the reality of eventual mortality in the face of chronicity makes the existence of those infected vulnerable. As observed by Machado (2012), AIDS brings to the fore a fundamental yet overlooked fact of life that every human being exists in a body. The many ways in which the HIV disease affects the body also influences an individual's perception of him/herself since the body is usually tied to one's subjective experiences of identity (Yang *et al* 2015). This is especially so because HIV contraction is an embodied experience which is mainly contracted through bodily fluids during sexual intercourse. This makes those living with HIV/AIDS to experience isolation, embodiedness and anxiety. Consequently

those diagnosed with HIV experience acute existential disruption and meaninglessness as they "assert their individuality through ultimate demise" (Markotic, 2003:176).

As noted by Reiter (2007), diagnosis of a terminal illness is one of the events that generate biographical uncertainty in individual biographies. This biographical uncertainty arises from the weakening or dissolution of standardized expectations of life development in a particular society.

HIV diagnosis is the first step in incorporating HIV/AIDS into an individual's identity, challenging their identity as a healthy person. This experience is a radical discontinuity to their life path project. For example, Cate, a 23 year old female graduate confessed that her life was unmade after she learnt of her HIV seropositive status while processing travel documents for further studies in Europe. The devastating news of her HIV seropositive status scuttled her bigger picture as a woman cut out for great things. She regretted her amorous past as the cause of her present predicament.

Mary, a 26 year old female teacher experienced her HIV positive diagnosis with shock and disbelief. To her, the diagnosis was like being given a death sentence by a judge without another option. She narrates:

> *Everybody in our village wanted their daughters to be like me……I was a role model because of my good virtues..! It was after I got my current job, that I had a sexual encounter with a colleague….. It happened only once. Two years later I got engaged to another man who was a staunch Christian. After dating for about eight months, we decided to wed in his local church. The church regulations required us to go for a HIV test before the wedding. I had no problem with this. However, when I undertook the test, it turned out to be positive. My world collapsed! I did not belief the doctor. I went to another hospital and the result was positive again. I did not know what to do because I was as good as dead.*

Other research participants saw their HIV positive diagnosis as the worst news to ever happen to them because it spelled doom for everything they had accomplished or planned to achieve; John, aged 35 years and a former truck driver elaborates:

> *I had seen how ill my wife was before she died……..it seemed she had HIV. I knew I had lived a reckless life as a long distance truck driver. After my wife's death, I lost a lot of weight. I also noticed thrush in my mouth and I was having nonstop coughs. I suspected I was HIV positive but I did not have courage to go for the test. When my cough persisted, the company doctor advised me to undergo an HIV test which turned out to be positive. It was the worst news I received in my life…. I was devastated……..I cried for my children who would be left as orphans and at the same time blaming the doctor for the bad news. I knew that was the end of my life!*

Other research participants felt that they were infected by people whom they had given their trust and therefore saw HIV diagnosis as a form of injustice inflicted on them. Kerubo, a 35 year old widow and mother of five children explains:

> *My husband infected me with the disease. He used to sleep with many women. I used to warn him that he would bring problems to us but…… I felt bitter when I tested positive. I cried for many days..... I was a virgin when I got married to him, having preserved myself for my husband, but look what he did to me……. I thought I was safe in marriage and never suspected that I could become positive…. I thought those who were at risk of infection were the unmarried ones and the prostitutes*.

As noted from these narratives, most research participants never went for the HIV diagnosis on their own volition. This is because such diagnosis was construed to be more disruptive to one's life path. For example, Ms. Cate, the 23 year old female graduate

learnt of her HIV diagnosis when processing her travel documents for further studies in Europe. Before then, she perceived HIV diagnosis as unnecessary evil which did more harm than good to an individual.

Nyangau, a 27 year old married man also believed that HIV diagnosis would hasten one's death even if one was professionally counseled. He elaborates:

> *My friend Moses looked very healthy. However, when he was diagnosed with HIV at the local hospital, his health drastically turned for the worst. Within six months he was dead……. I think knowing his HIV status hastened his death.*

This view by Mr. Nyangau was witnessed in other research participants. Ms. Kemunto, a 30 year old single woman, argued that knowing your HIV status when you have no health problems is like "trying *to know if you are a living corpse waiting for its time to be interred*". This knowledge alone is traumatizing than the HIV/AIDS itself. Ms. Kemunto elucidates:

> *It is a fact of life that we shall all die. No one has power to foretell when it will happen. Lack of this knowledge makes people to work hard in improving their life. However, if you know you are going to die soon more so from a very shameful illness, your life will be full of uncertainties ……think of a situation where every time you have fever you think the time of your death has come!!. These thoughts alone will kill you…….you can't plan anything…..your life becomes hopeless.*

The experience of HIV positive result "hastening death" is contrary to most studies in Sub-Saharan Africa which have highlighted its benefits. Studies by Kaler (2010), for example, have argued that knowing your HIV status is crucial in prolonging life as those found to be HIV seropositive are given free HIV treatment which can protect them from opportunistic infections which cause early death. However, the experience of HIV

diagnosis as a threat to an individual identity makes such benefits inconsequential as evidenced from Mr. Osugo, 25 year old;

> *I hate this diseased body, its meaningless and unreal to me. Whenever I look at myself in the mirror, I see a living corpse dressed in a suit and a tie…..the same way people see me. This is not the handsome body which was the envy of everyone. No one wants to associate with this body as it's contaminated and wasted! I am just tired of it. I don't understand why that "stupid" doctor allowed me to live with this body when I took poison*.

A critical look at Mr. Osugo's narrative shows that HIV diagnosis has drastically changed his previous identity making him feel that he is no longer the same person prior to diagnosis. This negative self image is reinforced by comparing his previous handsome body prior to diagnosis and how people see him now. With reference to Bury's (Bury, 1991) concept of biographical disruption, HIV/AIDS took symbolic experience of Mr. Osugo because it affected how he saw himself and how others saw him which influenced his identity. This shows the difficulties of managing HIV diagnosis because the society refuses to acknowledge HIV as a biological problem located in the individual's body. On the contrary, while the body is diseased, with the virus located in it, it is the society that creates "AIDS" through its stigmatizing discourses.

Ms. Jane, a 20 year old university female student felt that HIV diagnosis caused her to lose control of her body due to the virus and side effects of medication. This greatly disrupted her sense of self and meaning of life causing her to suffer psychologically as evidenced from her narrative.

> *After my secondary school education, I used to model for fashion companies. However, after HIV diagnosis I no longer model. Instead I hate myself because of the way I look. I hate going out because I look horrible…….skin rashes and thinning hair due to*

*the medicine I am using. I spend most of the time indoors looking at myself in the mirror wondering why I look so different. This has made me to spend a lot of money to buy beauty products in an effort to regain my beautiful body.*

As noted from Jane's narrative, the experience of HIV diagnosis heightens an individual's awareness of an evolving self, due to changes caused by the virus in the body. This makes the individual to be preoccupied with retaining the pre-diagnosis identity as a way of reducing the threat to his/her sense of self (Bury, 2001; Yang *et al* 2015). This causes emotional dispositions to an individual.

The loss of sense of 'self' was also evidenced through body mapping of some research participants. According to De Jager *et al* (2016), body mapping involves tracing around a person's body to create a life-sized outline, which is filled in during a creative and reflective process, producing an image representing multiple aspects of their embodied experience. In this case the researcher drew a picture sketch of each research participant's body on a piece of paper and asked them to describe how HIV diagnosis has affected their bodies.

Findings from body mapping showed that the experience of HIV diagnosis to the self was subjective (Ciambrone 2001, Faircloth *et al.* 2004). This subjectivity is informed by the socio-cultural discourses of an individual's socialized life path projects. Mrs. Nyakara, a 29 year old married woman with two girls, saw her diseased body as useless and unworthy of living because she couldn't bear a son after losing her uterus through forced sterilization due to HIV diagnosis. Her narrative illustrates:

*I was diagnosed with HIV when attending an antenatal clinic. I did not share this information with my husband because he was most likely to accuse me of infecting him with the virus. The doctor who diagnosed me advised that I must give birth at the hospital through cesarean section to avoid infecting my child. ……. On*

> *the day I started experiencing labour pains I went to hospital and was admitted. The doctor gave me a form to sign. He never allowed me to read it. Immediately I signed it, I was taken to theatre where I delivered a baby girl. I stayed in the hospital for five days before being discharged. A year later, I wanted to have another child, most preferably a boy. I went to the same clinic for advice given my HIV status. The doctor went through my file and carried out some tests on me and informed me that I could not conceive because my uterus was removed the last time I gave birth .....This information hit me like a thunderbolt… It was much worse than when I was informed of my HIV seropositive status! I felt useless, dying without a son to inherit my property and carry on my lineage! I hated myself and contemplated suicide.*

Mrs. Nyakara's perception about herself was influenced by the inability of her body to engage in social reproduction due the loss of her uterus. Among the Abagusii, it is through social reproduction that a man or woman gains social status and identity in the community (Levine *et al.* 1998). Although Mrs. Nyakara had a girl child, she felt useless and unworthy because she wouldn't give birth to more children and more importantly a son. This predicament is best exemplified by the proverb *Mwanya baiseke bange n'kerandi getakwoma, m'botaka botakoera* ( Literal translation: A home with many girls will receive many livestock due to dowry payment and hence have milk in abundance but the family will always be lonely and defenseless). This proverb argues that a house with daughters will not be poor in food and cattle (because of their labour and bride wealth) but will lack security and a son to propagate its lineage[6]. Consequently, engaging in social reproduction is more paramount than HIV diagnosis *……after the tests he told me that I could not conceive because my uterus was removed during the last birth .....This information hit me like thunderbolt It was worse than when I was informed of my*

[6] The Gusii lineage system follows the patrilineal principles that entail tracing one's descent in the male side.

*HIV seropositive status!* This means the risk of HIV/AIDS infection becomes secondary for those pursuing social status and identity through social reproduction.

Mr. Juma, a 36 year old male mechanic was diagnosed with HIV when he was donating blood to his brother who was involved in an accident. Few months later, he became ill and developed some complications which led to paralysis of the right side of his body. This made him to stop working and he entirely depended on his wife to provide for him and the family. This caused him to devalue himself as a man because culturally it is the role of a man to provide for the family (Masese, 2011).

Sufficing from the narratives of Mrs. Nyakara and Mr. Juma on their diseased bodies, it is clear that the problem of HIV diagnosis on individual lived bodies lies on the failure of their bodies to perform the ascribed social and cultural roles. This failure is problematic because it negatively affects their social status and identity in the community.

Apart from the destructive effect of HIV diagnosis on an individual's identity, the diagnosis was also found to affect the key source of identity which is motherhood or fatherhood. Among the Abagusii, motherhood or fatherhood is attained only through marriage (where a woman and man become wife and husband respectively) and the ability to have children and care for them. This accords an individual respect in the community. However, this is problematized by the fact that sexuality which is a key pathway to motherhood or fatherhood is the most prevalent mode of HIV/AIDS transmission (Setel, 1999; Gombachika et al 2014; Smith et al 2010, Mungwini, 2008).

Mr. Morara, a 28 year old man discovered that he was HIV positive during a recruitment exercise as a policeman. Though he was professionally counseled that he could lead a normal life and have children who are HIV negative through medical assistance, he was in a dilemma on what to do with regards to getting married. He didn't know how he could disclose his HIV seropositive status to his potential partner without injuring his own reputation; how he would protect his partner from infection and at the same time make her conceive, and worst of all, who would take care of the children if he died while they

were still young! Mr. Morara's dilemma was made worse by the fact that at his age he was supposed to have gotten married and sired children who could carry on his lineage. This devalued him as a man.

As noted from Mr. Morara's narrative, it's clear that failure to attain fatherhood due to HIV diagnosis is a major threat to one's identity. This is because HIV diagnosis becomes a barrier to the performance of social reproduction. This is problematic because among the Abagusii, if a man dies without marrying and siring children him and his family is stigmatized. This was symbolized by being buried with a piece of wood by his side (*korutwa omware*[7]*)* to signify a fulfillment of marital and reproductive goals that was never attained.

Among women, failure to become a mother due to HIV diagnosis is more tragic than in the case of men as explained by Ms. Nyabiage, a single woman aged 30 years, working as primary school teacher.

> *.....immediately after college, I was posted as a teacher not far from my home. To minimize expenses I decided to stay at my parent's house. All was well until I was diagnosed with HIV. When my parents knew of my status, they forced me out of our home. My mother told me that I was an embarrassment to them .....at my age I should have been married because younger girls than me had gotten married and were happily living with their husbands. She informed me that if I were married, I wouldn't have been infected with HIV. My father informed me that his home was not a cemetery for outsiders and more so for those dying from sinful diseases. I had no option but to seek for a transfer to a very far away school. Since I left home almost two years ago, neither my parents nor*

[7] *Korutwa omware* was something which was feared because of the associated stigma to the family and even to the dead. Although this practice of o*korutwa omware* is not so much practiced today due to the influence of Christianity, dying a bachelor is still feared and stigmatized by all ( Masese, 2011; Shadle, 2006).

*any other close relatives have bothered to inquire about my welfare.*

A critical look at Ms. Nyabiage's narrative shows that women suffer more with HIV diagnosis than men. This is because they lack social support due to their cultural position in the community. In the Gusii community, women are seen as outsiders in both their natal and bridal homes. In their natal homes a woman lacks proper identity until she is married. In their bridal homes, although she acquires her proper identity as she is integrated to the man's patrilineage because of her role of bearing children who will perpetuate her husband's lineage; she is still considered as an "outsider" by the man's lineage. Therefore in her bridal home, she is considered as an "insider" by her natal clan, yet her bridal clan considers her as an "outsider". This ambivalence in a woman "insider" and "outsider" position in her natal and bridal clans makes it hard for her to get social support from her immediate social networks. That is why Ms. Nyabiage's parents pushed her out of their home after she was diagnosed with HIV, and informed her that even if she died, she wouldn't be buried in their homestead because she was considered an "outsider'.

In addition, Ms. Nyabiage's predicament due to HIV diagnosis is worsened by the fact she is not married. This is because among the Abagusii, a woman's sexuality is believed to be safe or secure if controlled by a man in marriage. Therefore, any woman of marriageable age who is not married is perceived as a risk to the community members due to her " uncontrolled sexuality". This means that as a single woman, Ms. Nyabiage is to be blamed for her HIV seropositive status leading to her being stigmatized.

Among those who had attained fatherhood or motherhood, HIV diagnosis was found to be a threat to their identity as good mothers or fathers to their children. This threat arose from their inability to perform the socio-cultural roles as parents due to ill health and associated stigma of HIV diagnosis. Ms. Nyabonyi, a 36 year old single woman explains:

*As a single mother it is very difficult to meet the needs of my three children adequately. This has been made worse because of my ill*

*health due to HIV. It really pains me to see my children sleep hungry and unable to attend school due to lack of school fees. My eldest daughter is also involved in sexual relationships with older men. As a mother I don't have a face to advice her against those relationships…… I just fear bringing up any topic touching on morality and illness due to my HIV status…… as a mother I have totally failed!*

Other research participants felt that the fatal nature of HIV/AIDS posed a greater threat to their identities as mothers or fathers than the associated stigma. Jomo, a male businessman aged 29 years narrates:

*My major concern is about the future of our children. I am sure that sooner than later my wife and I will die from this disease which has no cure. Our children will become orphans ……they will not have anyone to care for their needs. This virus has destroyed my life and that of my family!*

However, not all individuals experienced HIV diagnosis as a threat to their identity. Instead, their HIV diagnosis was experienced as a mere disruption of their everyday life due to the limitations imposed by the illness. This experience was common among individuals who had experienced "a hard life" prior to HIV diagnosis and therefore never bothered to bracket off the illness as a means of protecting their identity, by either using various strategies to retain a pre-diagnosis identity or developing a new post-diagnosis identity. The life story of a 24 year old woman Ms. Chayo, underscores this:

*I was born in a family of three children. My mother was a single mother. Given that women in our community do not inherit land from their parents, my mother was forced to move to an urban area in order to fend for us. In town, we resided in a single room where my mother was engaged in selling illicit brew. The income*

*from this activity was not enough to meet our basic needs, so she supplemented it by engaging in sexual activities with some of her clients. The whole of our lives entailed living with uncertainty Sometimes my mum would be beaten and raped by her clients in front of us! This kind of life became normal to us. One day a client slept in our house..... I was about 13 years old then. After having sex with my mum, he came to where I was sleeping and raped me. I called for help from my mother but she was dead asleep. After the incident, my mother woke up and chased him away. I later learnt that the rape incident was my mother's plan because the man paid her more money. Since then she encouraged me to have sex with her clients as a way of supplementing our family income. Later, my mother was diagnosed with HIV and died of AIDS related complications. This meant I was the one to take care of my two siblings. I had no other source of income, and had to continue with my mother's business. ..... In this business my philosophy was living one day at a time. This is because in more than three occasions, I almost lost my life through injuries I sustained after fighting with some clients. The last incident which saw me admitted for three months also led to my diagnosis of HIV. This was not a surprise to me! I am now sick and unable to engage in my business fully rendering me almost a beggar. I am now dependent on people for my sustenance and that of my siblings.*

Ms. Chayo's life story confirms Williams (2006) observation that those people experiencing "a hard life" may not necessarily experience a chronic illness as a biographical disruption. "Hard life" in this case is seen in relation to an individual's wider life context, to mean a previous experience of a life threatening encounter with illness at personal or within a close social network such as the family. This experience of "hard life" is used to make sense of the new threat to life, by lessening its threat to an individual identity.

HIV diagnosis was also not perceived as a threat to identity in cases where an individual's personal actions is not blamed for the illness, but the prevailing contextual factors which necessitated the contraction of the illness. In this case the individual is not blamed as the cause of the illness but what made him/her vulnerable to it. This way, the individual is protected from blame and stigma associated with such an illness as observed in the case of Ms. Kwamboka, a 36 year old widow with four children.

Ms. Kwamboka lost her husband through a tragic road accident. The husband was the only breadwinner in the family. To support her children, she was forced to engage in sexual relationships with many sexual partners as a way of accessing resources to meet her children's needs. Unfortunately, she was infected with HIV. As the illness took toll on her, many community members empathized with her by blaming her widowhood as the cause of her illness.

As noted from Ms. Kwamboka's life story, her risky sexual behaviour was not blamed for her HIV seropositive status. Instead, her condition of being a widow which made it difficult for her to provide for her children was to blame. This means that her identity as a good mother to her children is not threatened by her HIV diagnosis. This shows that illness explanations are based on the cultural values and social relationships which shape people's interpretations to various illnesses (Kleinman, 1988). These interpretations are important in determining the identity of those who are affected by a particular illness.

Although HIV/AIDS is now regarded as a chronic illness which can be managed through antiretroviral therapy (ART) and a person can live a normal life, it is still construed as "imminent death". Consequently, those who are diagnosed with HIV experience feelings of uncertainty about their future due to imminent loss in personal social and economic life. These losses encompass loss of self, relationships with significant others and economic opportunities.

As found out in this study, some research participants experienced physical changes in their bodies due to HIV infection and side effects of medication. This caused them their

self esteem. As a consequence, they tried to alienate themselves from the outside as a way of cushioning themselves from stigma and oppressive social structures. Mr. Nyamweya, a 34 year old long distance truck driver elaborates:

> *.....I noticed a lot of changes and after I was diagnosed with HIV. There was a skin infection all over my body.....which was scary! This made me to be always cautious on how I dressed. I also experienced weight loss and this made me think that it was almost time for me to die! These thoughts made me to devalue myself completely. I felt like I was a walking corpse. I didn't have the courage to associate with my acquaintances because i believed they were seeing me as the next person they will be burying..... I resigned myself to loneliness.*

Mr. Roinya, a 60 year old man, who became physically disabled as a consequence of HIV/AIDS related meningitis, lost his self esteem as a result of depending on others to carry out basic biological functions such as going to the toilet. This was worsened by the fact that at his age he was dying from a stigmatizing illness. He narrates:

> *I have grown up children who are married. I am a grandfather and father.in law to many. My social status commands respect. But this disease has made me lose face among all people. ...Though people cannot say it openly to my face, they wonder how a man as old as me could get an illness associated with young and immoral people! .... I am paralyzed and I have to be carried around by very young people even when performing basic biological needs....I just wonder how people see and think about me!*

The experience of Mr. Roinya's HIV diagnosis can be understood in relation to the widespread cultural stereotype that old people are asexual (Taylor et *al* 2011). Therefore being infected with an illness which is associated with immorality is stigmatizing. As a

consequence the old people living with HIV are doubly stigmatized due to their age as well as their HIV status (Nevedal *et al* 2016).

The loss of self esteem also arises due to self devaluation because of the guilt feelings following HIV diagnosis. The guilt feelings in this case were related to beliefs of having engaged in immoral sexual behaviour which resulted to infection and the concern of having infected others prior to the diagnosis as evidenced in Mr. Mariera, a secondary school graduate teacher aged 43 years:

> *I look at myself and wonder why a highly educated man like me would engage in unprotected sex with commercial sex workers whenever I went out for entertainment! I never lacked anything at home.....my wife, is very young and beautiful, yet here I am infected with AIDS! I feel so dirty and unclean. I really regret my former lifestyle but my only hope is that I have not infected my wife. Sometimes I ask myself ....how many daughters and wives I have killed because of my immorality!*

In addition, others experienced loss of self esteem when they experienced rejection from their significant others as a result of changes in their self image due to physical illness. Ms. Gesare, a 28 year old female working in a tea factory explains:

> *Before I was diagnosed with HIV, I was very popular among my colleagues. We could meet good restaurants for entertainment and share jokes in social media platforms. However, when I developed rashes all over my body, most friends avoided me. We could agree to meet for lunch but few minutes to the time, the person would call to postpone the lunch until a later date. This became so common amongst my colleagues. For those who would honor such dates you would see how uneasy they were being with me. This made me*

> *feel so low and depressed. I thank God for the ART because now i am living my normal life.*

Apart from making people lose their self esteem, HIV diagnosis also had a profound effect on other people's day to day living. For example, Mr. Otumbi, a 32 year old former supervisor in a local supermarket, observed that he was a very active and dependable supervisor in his work place. However, with HIV illness he found himself spending most of the time in hospital as a patient than in his work place. This made him to resign from his work place because of his ill health. To him, HIV changed him from being an active and dependable person to a patient.

Grace, a female nurse aged 25 years lost her job due her HIV seropositive status. To her, experiences of being rejected by colleagues and patients were intolerable for her to continue working. She explains:

> *When patients in the hospital where I was working knew of my HIV seropositive status, none of them wanted my nursing services. I would take the prescribed medicine to a patient, and the patient would refuse to take it for fear of it being contaminated with the HIV virus. My colleagues would reject my company when checking patients in various wards. The working environment became horrible and I quit my job.*

Loss of careers due to HIV diagnosis exposed a number of people to financial difficulties. This made them to change their lifestyles. For example, Grace the nurse, moved from a middle class residential estate she was living prior to her HIV diagnosis to a low class residential place to cut on the cost of rent. Similarly, Mr. Otumbi moved back to his rural home with his family. This abrupt change of lifestyle had immense psychological stress on them as they had to come up with connoted explanations to justify their newly adopted lifestyles without alluding to their HIV seropositive status.

The existential disruption due to HIV diagnosis has also been widely discussed in popular discourses in Kenya. For example, in Mutahi Wahome's (2004) *The house of doom*, the diseased body of Mbela who is the main character is typified as nomadic and incapable of relationships. The body is unable to find recognition and support for its sickness and is boxed into a corner where it can neither love itself nor others. Rendered nomadic by pain and suffering, the diseased body has erected a wall around itself and refuses to be assisted or comforted. This sense of loss of self evokes Albert Camus (2003:51) postulation that:

> *.....although life may be meaningful, meaning often eludes those who find themselves unable to connect with either their own inner self, other people, or some source of grounding..... The inability to overcome one's separation becomes a spiritual, intellectual and an emotional obstacle to one's search for meaning.*

Similarly, in the text by Francis Imbuga (2004) *Miracles of Remera*; the tribulations of young adults as they negotiate the challenges posed in their lives by the reality of AIDS are recounted. The text is set in the fictional country of Remera whose tranquility has been disrupted by HIV/AIDS; the deadly disease which decimates most of its inhabitants. The protagonist in the text is Ezra Maiyo, a talented young man who is determined to make the best out of his life. However, his life, dreams and ambitions are disrupted when he meets a young lady, Brenda, after the comrades' party where they both spend a night and consummate their love without protection because he was too drunk. Years later, Maiyo learns to his shock that he is HIV positive after donating blood at Avenue hospital. Almost the same time Brenda is diagnosed with HIV following mandatory testing when she was joining permanent employment as a teacher. The rest of the text relates to Maiyo's struggle with the shuttering reality as he tries to live a normal life as an HIV/AIDS patient in the university, an existential disruption that compels him to withdraw to himself and experiment with herbal medicine in a bid to negotiate his condition.

In addition, popular local musicians have also composed many songs about the existential disruption of HIV/AIDS on individual lives. Among the Abagusii, for example, a popular local music band, Bana Sungusia composed and sang a song in 2014 titled ‘‘*Ukimwi*’’ (HIV/AIDS) (https://www.youtube.com/watch?v=fixobqa15KE). In this song the artists figuratively sings how the diseased body from HIV/AIDS illness suffers and how this suffering body not only affects the subject's life path project but also his/her significant others. However, the artists lay blame on those infected by HIV/AIDS because of their sexual immorality.

Although most popular discourses about HIV/AIDS acknowledge its existential disruption, they often blame those infected for not practicing safe sex. This causes the infected persons to be discriminated and stigmatized, yet sexual behaviour is not only a function of individuals but also a structural and environmental factor as well (Bibeau *et al* 2002). As a consequence those diagnosed with HIV acquire "a spoilt identity" which poses them a problem of self construction and self presentation in relation to the significant others in their everyday lives.

**Social death and stigma**

Varas-Diaz *et al* (2003) posits that the body is the vehicle for interaction with the world and others and that it is through it that people experience the HIV epidemic. They further assert that in social interactions where bodies are embedded, the consequences of infection are evidenced in stigmatization. The process of stigma construction and reception culminate in an erasure of the bodies, lives and identities of people living with HIV/AIDS (Subotzky, 2004).

HIV/AIDS is directly related to sex and death, which are two aspects fundamental to the questions of human existence which also constitute two of the greatest social taboos. It is this link between sex and death that engenders deep rooted fears around the disease and dying on one hand and social disgrace and deviance on the other (Marais, 2000).

The association of HIV/AIDS with notions of sex and death intensifies its complex association with sickness, contagion, loss and bodily death on the one hand and sexuality, pleasure and survival on the other, all experienced through and intimately connected with the human body which is trapped at the centre of discourses surrounding the epidemic. HIV positive bodies are therefore seen as "invasive agents, who threaten the social order and place public health at risk (Sontag, 1998). Through their association with a state of decay, diseased bodies become sites of social unease, representative of contamination of life by death (Varas-Diaz *et al*, 2003).

These anxieties surrounding diseased bodies intensify stereotypical phobia of the disease and its apocalyptic reverberations which is reacted through denial expressed through AIDS related stigma. As individuals and collectivities locate the disease beyond a series of perimeters in order to retain and defend spaces in which normality and the known reign (Marais, 2000), it leads to projection as a global tendency to externalize blame and responsibility for HIV onto the stigmatized other (Auge *et al* 1983; Gilman 1995; Sabatier, 1988). Therefore AIDS stigma reflects prevailing prejudice in which codes of sanctions are slotted neatly into moralistic narratives of deviance, accountability and just punishment (Marais, 2000).

Notions of visibility and punishment are central to phenomena of AIDS stigma. Stigma is recognition of difference that is evaluated negatively and which resides in the body (Subutzky, 2004). This visual dimension of the diseased body makes it a target of surveillance and regulation through regimes of discipline and punishment, as Faucalt (1995) puts it, as attempts are made to either zone off the diseased bodies or discipline them into health. This is especially so because HIV positive bodies are seen as unfathomable and out of control and are seen to inaugurate a crisis in those systems of power concerned with the regulation of bodies (Thomas, 2001).

The crisis inaugurated by AIDS and the regimes of representation which make the lives and bodies of some visible, leads to discursive erasure of HIV positive bodies. This stigma becomes internalized in the form of bodily shame and guilt with its intimate

association of identity and bodily perceptions. The body is understood as a socially constructed entity through which people develop discourses (Varas-Diaz *et al* 2003), and bodies come to be seen as visual signifiers of ourselves, constantly on display, where they are interpreted and decoded by ourselves and others.

HIV/AIDS stigma compounded with the existential dilemma of the diseased subjects is an impediment to prevention and treatment of the disease. Stigma is one of the single most factors producing and exerting negative psychological effects of HIV/AIDS. The people infected are stigmatized and discriminated against for a variety of reasons which include the capriciousness and intransigence of the illness and its association with a death sentence. AIDS phobia emanates from ignorance and misconceptions of the syndrome where conflicted discussions produce polarizing knowledge about the disease, while transmission is associated with transgressions of societal morals.

According to Goffman (1963), stigma applies more to the disgrace associated with bodily signs; it is the situation of the individual who is disqualified from full social acceptance through socially constructed criteria of categorization. In life, HIV diagnosis engenders immediate social death even to the HIV seropositive but asymptomatic individuals whose life expectancy is often better than persons with cancer and cardiovascular disorder.

In *culture, health and illness*, Helman (2000) opines that social death may precede physical death by a remarkable period where individuals are still alive physically but less alive socially, both in the eyes of the family and the wider society. To him, those confined to institutions such as prisons, old age homes and hospices for the terminally ill have undergone a form of social death before their biological demise. He notes that the diagnosis of a serious disease such as AIDS may lead to social death of the individual and may engender a nocebo[8] effect aggravating the individual's health. In the case of terminal illness, patients leave their normal life behind and enter a state of limbo characterized by

[8] Nocebo: from Latin root "noceo", "I hurt", is the negative effect on health beliefs and expectations. As Hahn and Kleimman put it, belief kills; belief heals. Cited in Cecil Helman (2000), *Culture, Health and Illness*, 4th edition, 207-208, see also Hahn R (1997): The nocebo phenomena: concept , evidence and influence on public health" Prev. Med.26,607-611

a sense of vulnerability and danger. HIV/AIDS is a disease traditionally laden with guilt, prejudice and blame. Popular representations of the pandemic contain elements of bias, stereotypes, misconceptions and/or falsehoods. HIV disease foregrounds the body as a commoditized or polluted entity, which taints the social standing of the individuals and their relationships (Yankah, 2004).

In this study, many research participants view AIDS as a social stigma and frequently experience prejudice and discrimination. They use the phrase "being judged" to characterize the feeling of prejudice and discrimination. Grace, 25 years old nurse felt that she was socially stigmatized as a result of being infected with HIV. She said:

> *.....when my colleagues knew I was infected with HIV no one wanted to associate with me. They avoided any contact with me. They locked one toilet for their use and left the other for me. This was not only restricted to my colleagues but also to the patients who never wanted anything to do with my nursing services.*

Mr. Otumbi, as described earlier also narrated his experience of being discriminated and rejected because of being infected with HIV:

> *.....in our rural home, I noticed that most people were not at ease with me whenever I interacted with them. I comforted myself that they were not used to me given my long stay in town. One day while going to town to buy medicine, I boarded a bus at the main stage. When the other passengers saw me, most of them alighted. I did not understand why until the driver came to me and in anger told me to get out of the bus because nobody wanted to travel with me, for fear of me infecting them with AIDS. I really felt devalued especially when I got off the bus and everybody started shouting at me that I should desist looking for people to infect with my illness and instead seek forgiveness for my immoral ways.*

In some cases those diagnosed with HIV never sensed they were being rejected by others because people covertly avoided them. Mary, a 26 year old teacher prepared a birthday party but none of her invited friends came. She explains:

> *I didn't know that even my close friends did not want to associate with me until I invited them for my birthday. I prepared food and drinks for the day. However, none showed up. Later I came to learn from rumors that they did not honor my invitation because they feared I might contaminate the food with the virus so that they could be infected like me. Others felt that the celebrations could be my farewell to them as I was going to die soon. It really pained me!*

Mary's experience was also shared by a 31 year old farmer Mr. Onchomba:

> *After my wife's death, I could go to one particular hotel to watch football as a way of avoiding stress. Every time I went there I found a specific seat reserved for me..... even there was one specific glass for me whenever I wanted to take a drink. Initially I never paid much attention to all these until one young man refused to be served using the glass I had used. He protested bitterly. ..... I realized how people were avoiding me covertly.*

The experience of social rejection and discrimination was not restricted to those infected with HIV only but also to their immediate family members. Mr. Mariera, the 43 year old secondary school teacher elucidates:

> *In school, my children are not allowed to play with other children. Many parents have cautioned the school administration not to allow any close contact of their children with mine. They have gone ahead to threaten to withdraw their children from the school*

*if their demand is not observed. The school administration has gone ahead to institute various measures such as allocating my children specific seats in class.*

Apart from experiencing social rejection, those infected with HIV were denied opportunities to participate in social activities in the community. Ms. Nyachama, a 36 year old widow was denied membership in a woman merry go round group "*sebokia*[9]‘‘because other members felt that she had an uncertain future due to her HIV seropositive status. She explains:

*Everybody knew my husband died from AIDS and that I was also infected. I thought with this, community members will not have any excuse to discriminate me in any community activity. So when I visited the chairperson of our local women self-help group with an intention of becoming a member, She requested for time to consult other members of the group over my request. Three months later and no response, I decided to go and inquire why I hadn't been given a chance to join the group. Initially she was not keen on letting me know what the members had decided but after some time, she informed me that due to my poor health and unpredictable future, I wouldn't be allowed to join the group.*

Mr. Nyarongi, a 25 year old church youth leader was relieved off his duties after he was diagnosed with HIV. According to the church leadership, he was not a good example to guide the youth on issues of morality. His HIV diagnosis was seen as resulting from sinful acts of immorality which in themselves are against Christian teachings which emphasize sexual chastity until marriage.

[9] “Sebokia” means to assist to prosper economically. In the study site and generally in Gusii “Sebokia” refers to a group of people who have come together to assist each other economically. The group works in “a merry-go-round system” where members contribute a stipulated amount of money either every fortnight or monthly which is then given to one member in rotational basis according to their agreement.

The stigma and social death suffered by the HIV/AIDS diseased subjects is a reflection of hegemonic bio-power in the society. According to Nzioka (1996:571), part of the process of making illness is to emphasize differences, where anyone who has overt physical and social attributes which are different is socially constructed as more susceptible to illness. In the process, those seen as 'different' are seen as enemies who should be avoided at all costs.

In conclusion, "stories of sickness, of people with AIDS are texts of suffering that can show evidence how our cultures, communities and individuals elaborate the unique textures of personal experience out of an impersonal biological illness" (Farmer and Kleimann, 2002 :139). As observed from the foregoing illness narratives, it's clear that HIV diagnosis imposes limitations to an individual in everyday life through stigma which leads social death. As a result an individual's existential life is disrupted causing him/her to calibrate new ways of life or relations.

**HIV/AIDS diseased bodies and everyday lived life**

As observed from the foregoing illness narratives, it is clear that HIV diagnosis imposes a heavy toll among diseased subjects. This makes people living with HIV/AIDS alienate to themselves from the outside world as a way of cushioning themselves from stigma and oppressive structures (Le Marcis, 2012). This destabilizes and undermines their sense of self as existing beings.

Consequently, those infected with HIV/AIDS use different modes of survival tactics because of the disruptive nature of the illness. They are forced to undergo an existential reorientation whereby they make new arrangements and quests for their new life pathways as they witness the collapse of their former life-world. This reconstruction in the wake of a debilitating illness necessitates reworking an understanding of the self and the world and redefining the disruption of life itself so as to create order from chaos and render life meaningful (Becker, 1998:4).

As noted in this study, the way individuals negotiate the disruption of HIV/AIDS illness in everyday lives was first and foremost influenced by the socio-cultural benefits of HIV disclosure or non-disclosure. According to Mayfield *et al.* (2008), HIV disclosure refers to willingness of people living with HIV/AIDS to reveal their seropositive status to other people. This disclosure is taken as beneficial to those infected in that it facilitates access to social support and treatment (Vu *et al*, 2012). However, in this research context, these benefits were secondary to the social and cultural factors that shaped the notions of what it means to be a 'person'.

Among the Abagusii, a person is understood as being constituted by relations with others, through kinship and other forms of substantial relatedness and through a flow of substances that link one person with others and the environment. This understanding of personhood tends to value relationships between people over boundaries around them, and regard the person as composite and overlapping with other persons rather than autonomous and indivisible and is mostly expressed as *"I am because they are"* (Foster, 2006; Mbithi, 1974). This is contrary to Western understanding of personhood which often emphasizes individualism and boundaries.

An idealized individual body in this context is an autonomous and indivisible organic unit, which depends on completeness and boundedness for its wellbeing. HIV/AIDS illness in this case is understood in terms of blocked pathways or infringed boundaries in an individual lived life. This is then countered by taking different actions which aim at re-establishing firm boundaries around the body and person. These actions are done by taking into account the socio-cultural benefits of disclosure or non disclosure of a person's social status and identity in time and space as hereafter discussed.

*Breaking with the past and living a virtuous life*

Research participants, who believed that they were infected with HIV because of their engagement in risky behaviour, stopped such behaviour and embraced a new moral life. Most of these research participants accepted their HIV diagnosis because it was not a surprise to them. They tried to engineer their lives in order to regain, restore and preserve

an accepted identity and status. Ms. Nyambeki, a 29 year old former sex commercial worker with three children elaborates:

> *I had worked as a sex commercial worker for about six years. It was not my wish to be in this trade but the need to provide for my three children since I am a single mother. Through the years, I had seen a number of my colleagues die from this disease. I knew my time would come as I was involved in this dirty job. One day I went to hospital for treatment of a recurring skin infection. The doctor tested me for HIV and I was positive. Though these results were not a surprise to me, the thoughts of leaving my children alone when I died really bothered me. I knew no one would take care of them because of my immorality! I had to change my way of life. I decided to quit this trade and to have nothing to do with men! I then joined one of the evangelical churches where I confessed my sins and got saved. As a Christian, I trust that one day God will do a miracle and I will be healed from this illness. I am now a member of a group of preachers who are spreading the word of God to non-believers. I find this a higher calling than anything else in my life.*

A critical look at Ms. Nyambeki's narrative shows that she was aware of the social link between sexual risk, death and the "spoilt identity" and its consequent negative impact on her and other significant others in her life. Therefore she had to rework on her "spoilt identity" by stopping her trade as a commercial sex worker and get saved. Her religious conversion in an evangelical church had profound implications on her identity; one, her confession of her past sins and asking God for forgiveness is believed in evangelical churches to discard the past spoilt identity and bring forth a new good identity; two, her belief in miracle healing to restore her health from HIV/AIDS illness, and lastly, her involvement in religious activities marks a new beginning of doing moral activities for the benefit of the society. All these fortify her new identity.

Arising from Ms. Nyambeki's narrative, religious conversion can be understood both as a ritual passage linked to critical biographical experience and as a practice of care

(Burchardt, 2009; Kotobi *et al* 2010). It is a biographical experience because it gives birth to a new biography by discarding the old self and its attendant identity. In this case a "new" person with a "new" identity is born. It is a practice of care because the contingency of life with HIV is bracketed in the phenomenological belief of miraculous healing.

*From HIV/AIDS patient to expert*

Mrs. Nyankoni, a 25 year old business woman had gone for a prenatal check up where she was diagnosed with HIV. This information devastated and shocked her since she had just been married for one year and was three months pregnant. When she went home, she wanted to share this sad and shocking news with her husband but could not gather the courage to do so and so she kept it to herself.

Few weeks later, while cleaning the house, she found some medicine hidden in her husband's belongings. She was already on antiretroviral therapy (ARV) drugs and so she knew what exactly they were for. When she confronted her husband, he did not deny it, but admitted that he had been on ARV for a while and was afraid to tell her because he feared he would lose her. This confession really broke her heart. She couldn't understand how a person who confessed undying love for her would deliberately infect her with HIV. She couldn't fathom living with HIV and the experience of dying from it. She contemplated suicide but ruled it out because it would shatter her immediate family. As days went by, she and her husband lost a lot of weight and they were the subject of gossip in the village. This caused them to be stigmatized and socially excluded. Despite this, she continued following the doctor's advice and taking her medicine. Three months later, while attending a prenatal clinic, she met a HIV counselor who had lived with the disease for 15 years. The counselor convinced her that HIV diagnosis was not a death sentence and one could lead a normal life and give birth to HIV free children. This really encouraged her and three months later, she gave birth to an HIV free baby boy.

Though Mrs. Nyankoni accepted her situation and was living positively, her husband was emotionally stressed. He started indulging in alcohol and refused to take his medicine as

recommended by the doctor. He later died due to AIDS related complications. The demise of her husband ushered in floodgates of accusations. She was accused of infecting her husband with AIDS and consequently was rejected and socially excluded by her in laws and other members of her family. She was the subject of gossip which in turn led to the closure of the small shop she was running as all the customers fled. When she sought refuge at her local church, people there also ignored her.

Alone and dejected, Mrs. Nyankoni decided to confront the situation on her own. Since she had accepted her HIV seropositive status and knew that it was not a death sentence, she started educating people about HIV/AIDS. This brought an end to the gossips. Noting how successful this strategy was, she became more aggressive in organizing talks to various groups about HIV/AIDS as a way of fighting the stigma and empowering people on how to avoid risk of infection, and how to live positively for those who were already infected.

With time her efforts were recognized not only in her village but far and wide. This made her a role model in the community. In all public functions she was given an opportunity to talk about AIDS as a way empowering community members. She undertook various courses on HIV/AIDS in order to equip herself with more knowledge about the disease. This drastically gave her a lot of respect in the community to the extent that she was nicknamed the "AIDS Doctor".

From Mrs. Nyankoni's life story, she engineered her life and identity by managing HIV/AIDS stigma through public disclosure of her HIV status, thus assuming the role of a "moral career patient" (Goffman, 1990).

*Witchcraft "theory" as a way of coping with HIV/AIDS disruption*

In most non-western communities, an illness whose "cause" cannot be empirically located or which defies local and scientific medicines is explained as an act of witchcraft. With HIV/AIDS, people who are infected invoke witchcraft as a way of accepting their diagnosis by shifting its social meaning. This way they do not suffer disgraced identity as

they are seen as victims of malice or revenge rather than of their own social transgression.

Mr. Tom, a 35 year old farmer agrees that he must have been predisposed to HIV infection through his promiscuous life. However, he still thought that being HIV positive was not a "natural" event since some of his friends had had more sexual partners than him and yet they did not have HIV. He therefore questioned the biomedical germ theory of diseases by invoking witchcraft to be the cause of his illness. Tom explains:

> *When I started constructing my house, my neighbors were not happy. I know one particular old woman who does not want anyone to prosper in our village. In one of the days when I went to check the progress of the house I found her staring at it. I knew she was up to no good. Hardly one month passed and I was diagnosed with HIV! If it wasn't for that house, I wouldn't be in this situation.*

As noted from Mr. Tom's narrative, witchcraft is not only an alternative explanation for HIV/AIDS vulnerability, but also a way of absolving one's self from responsibility of being infected. This way, the HIV/AIDS stigma is modified and the person easily enlists sympathy from the significant others.

*Ambivalence as a way of coping with HIV/AIDS disruption*

Another way of coping with HIV/AIDS disruption is by taking on an ambivalent view of the HIV illness through the process of redefining the illness in a language that plays down its negative implications. The accuracy of the biomedical aspects is not contested, but the social explanations or justification of the illness trajectory is overemphasized.

Mr. Kayaga, a 42, year old man was experiencing various complications from HIV illness. He explained each of them independently and tried to justify why they were happening at that particular time.

> *For a month I had this persistent cough because of the dry weather. I took medicine which made me to have severe diarrhea. This made me lose a lot of weight. At least now I have started regaining back my health. I think my spending most of the time in bed has made my body to react to the new beddings my wife bought recently. This has caused me to have skin rashes.*

As observed from Mr. Kayaga's illness trajectory, each illness episode is normalized by treating it independently as a side effect of the ongoing treatment of "normal or natural illness". By doing so, the real cause of illness which is HIV is camouflaged. In addition, by redefining the illness as "normal" removes the notion of death which is associated with HIV. A "normal" illness is mostly treatable with known medical remedies and poses no risk to the infected or the affected.

Other research participants coped with HIV/AIDS disruption through a cognitive process of redefining their diagnosis by allocating themselves a category of "almost healthy," between the normal and the sick. This is common among those who are still asymptomatic.

> *The doctor told me I have HIV and not AIDS. This means I am almost healthy and can continue with my everyday activities provided I avoid risky behaviours like having sex with commercial sex workers. So as long as I watch my behaviour I won't be sick* (Mr. Osinde, 27 year old Driver).

As noted from this account, Mr. Osinde is trying to deny the "spoilt identity" by engaging in impression management whereby he delinks HIV from AIDS. By doing so he presents himself as "better than those with AIDS" and thus dismisses the spoilt identity by defining himself as "almost healthy". This shows that becoming infected with HIV is not simply a matter of viral infection, but a contingent of interpersonal interaction and definitions. Therefore, the successful transformation of HIV into an illness involves

sophisticated negotiations by a variety of parties which will later determine the specific identity to be acquired.

*Migration as a way of coping with HIV/AIDS disruption*

Lorna, a 28 year old woman had just secured a job in a tea factory as an administrator. The salary was good and she rented a house near her work place. One year into her job, she became seriously sick and was admitted in a nearby hospital. Initially the doctor thought she had acute malaria and typhoid. After a few days of treatment there was no improvement. The doctor recommended a series of tests including HIV. All the other tests turned out to be negative except that of HIV. This shocked Lorna so much. Not in her wildest dreams did she ever imagine to be HIV positive.

Since her CD4 count was low, she was put on antiretroviral therapy (ART) immediately. Since she was covered by her company, her sickness became known to her workmates. People delved into her personal life until everyone knew that she was HIV positive. After recuperation, she went back to work. At the workplace, she felt socially rejected as there was a lot of gossip about her life. She really felt betrayed by her workmates. She could not take the humiliation anymore and decided to resign and move to a new place where she was not known. She hence opted to use her middle name which was not common to many people. This way she cushioned herself from social stigma.

**Summary and conclusion**

Using illness narratives of those diagnosed with HIV, this chapter shows the ambiguity of social construction of HIV/AIDS as a manageable, chronic illness and as an imminent death sentence in every day live. As noted, those people living with HIV/AIDS face a lot of difficulties in adjusting to their new disrupted lives due to imposed limitations of the illness. These difficulties are centered on the desire to resist the perception of their condition as a death sentence and at same time trying to (re)negotiate their threatened identity within the larger community in which they exist.

## CHAPTER THREE

## THE ABAGUSII, THEIR LAND AND WAY OF LIFE

### Introduction

This chapter provides a background material on the Abagusii as a people, their land and way of life. In discussing these aspects, this chapter examines how the values espoused in these aspects influence their conception of life and death which in most cases emphasize the regeneration of life through social reproduction.

### The Abagusii and their land

The Abagusii is a community of Bantu who inhabit Kisii and Nyamira counties in the Western side of Kenya. Kisii County has nine subcounties including; Masaba South, Kisii Central, Marani, Kisii South, Gucha South, Gucha, Nyamache, Sameta and Kenyenya, while Nyamira County has five subcounties which are; Manga, Nyamira South, Nyamira North, Borabu and Masaba North (Kisii County Development Profile, 2013; Nyamira County Development Profile, 2013). Both counties occupy an area of approximately 2196 square kilometres and they are situated between a longitude 35 30' and a latitude 0 30' South.

The land is relatively hilly, and the terrain rises in the southern direction to an altitude of 7,000 feet and slopes westwards (in the direction of Lake Victoria) reaching an altitude of 4,500 feet at the lowest. The high altitude has a great influence on the annual mean temperature. In the North West, the annual mean temperature is $14^0$ C and $18^0$ C. On the east, where the altitude is higher, the mean annual temperature ranges between $26^0$ C and $30^0$ C. On the west the maximum mean temperature ranges between $26^0$ and $30^0$ C. On the eastern sides the temperature ranges between $22^0$ C and $26^0$ C (Akama and Kadenyi, 2006).

The climatic condition of Gusii region is highland equatorial with a modal rainfall distribution. The rainfall distribution is influenced by the Inter-tropical Convergence Zones (ITCZ). March to June constitutes the long rain season while October to December

the short rain season. Rainfall exceeds 1,500mm per year and is able to support diverse agricultural activities and animal husbandry.

The Abagusii are patrilineal and patrilocal people deriving their name from their founding father Omogusii. The Gusii oral traditions show that they originated from a mystical place called "Misri[10]" (Akama, 2006). They moved from Misri which is North West to their present day Gusii land, over eight hundred years ago taking an Easterly direction. They settled first near Mount Elgon region in Western Uganda. At this time, they belonged to one family with the Kuria, Luhya, Meru, Kikuyu and AKamba ethnic communities.

From Mount Elgon, the Gusii settled in Kisumu in the middle of 16th century (Akama, 2006). However, due to unfavourable climatic conditions for crop farming, they were forced to move to the Kano plains. At the Kano plains they started experiencing nocturnal raids from the Maasai who were after their cattle. This forced them to move to high altitude areas of Manga. Due to increased population pressure relative to resources, several groups of the Gusii started dispersing to various parts of the present Gusiiland.

The Abagusii consist of seven contiguous, but politically autonomous clans namely; Abagirango, Abagetutu, Abanyaribari, Abanchari, Ababasi and Abamachoge. They have four totems which they relate to. Abagirango relate to *Engo* (leopard), Abanchari relate to *Engubo* (Hippopotamus), Abasweta (consisting of Abanyaribari, Abagetutu and Abamachoge) relate to *Engoge* (Baboon) and Ababasi relate to *Enchage* (Zebra). This classification is for the basis of exogamy and establishing a sense of mutual obligation to group members (Nyamongo, 1998). In addition, they are perceived as a harbinger of good omen and prosperity (Masese, 2011).

[10] Most Bantu mythologies trace their origin to Misri but the exact spatial location of this place is not known. One school of thought contends that Misri is the same place as the biblical Egypt in North Africa. However, this appears unlikely as there is no collaborative linguistic or ethno graphic evidence to support this theory.

Each clan has its own land which is separated from that of other clans through distinct boundaries. Access to this land is only through being a member of a particular clan. The clan land is further subdivided into portions of family. Under this customary land tenure system, each family has exclusive rights to use the land the family holds. This means that all rights of land ownership and its usage are derived from clan membership by way of inheritance (Masese, 2006).

The land allocated to each family belonged to the family patriarch (father) who allocated it to his sons[11]. However, in a polygamous family, the father allocated his land to his different "houses[12]" of his family through what Hakansson (1994) calls house property principle. In this principle, each wife and her children constitute a house which according to customary law is jurally and economically independent in relation to other houses in the polygamous family. In this case the father allocates each "house" their land and then each "house" reallocates to their sons. This means all the land allocated to one family belongs to the father as its authority and it passes to the different "houses" of his family through the wives.

In recognition of this house property principle, women in a polygamous marriage who have no sons to inherit their land are allowed by tradition to "marry[13]" a surrogate wife and choose a mate for her. The children born out of this arrangement are of the woman with no sons or children. The purpose of this woman to woman marriage is to ensure that the family property bestowed to each woman "house" remained there for the continuity of her lineage.

[11] Inheritance of family land was through male lineage only.
[12] "House" refers to a distinct family of a particular wife in a polygamous marriage.
[13] This is where a woman who had no sons marries a young woman for the purposes of producing an heir, since women have no inheritance rights (only through their husbands) and cannot continue the family line. According to Gusii customs, the older woman is the dominant partner and generally dictates who should father the potential heirs by her "wife". The children born in this arrangement are for the woman who made this arrangement. See Kjerland K (1998):"When African women take wives: A historical overview." UPPSALA Univeritet Repro HSC UPPSALA Available at: https://nai.diva-portal.org/smash/get/diva2:460914/FULLTEXT01.pdf Accessed *on 2Oth September 2016.*

Land among the Abagusii is not only seen as a form of wealth passed on from father to sons but also has a cultural significance to the lives of members of the community. Whereas inheritance of land by the sons from their fathers symbolized the attainment of adulthood status, it is only on the inherited land that one exercised the attributes of adulthood. For example, it was mandatory for any male of marriageable age to build his own home[14] at the inherited land before he marries. This signified his readiness to start his own family which is an important avenue in exercising his own authority, independence and decision making as an adult person. In the community it is common for community members to scorn those people who have not built “a house" in their ancestral land even if they have one elsewhere.

Land is also crucial in the performance of rituals associated with the last rite of passage which is death. Among the Abagusii, it is mandatory for every person to be interred in a place where his ancestors were interred to show belongingness, communion and reunion (Ntabo, 2006). This way the dead person's spirits is elevated to the realm of ancestors which is a revered group that continues to be of cultural significance to the living. Hence, when a person is interred away from his ancestral land, reunion and elevation to the realm of ancestors is believed not to take place. This is because one's ancestral spirits are believed to reside in a particular geographical location within a clan where one is a member. Therefore interring a person outside his ancestral land causes the dead person's spirits to be problematic to the living kin.

The cultural significance of land had also profound influence on women identity and sexuality. According to Masese (2011), it was only through marriage that women not only acquired proper identity as adults but also got user rights to community land[15]. This user rights were not only restricted to meeting everyday sustenance but also a decent site for burial. As observed by Shadle (2006) women were seen as outsiders in their natal

[14] Among the Abagusii a "home" is a house which one builds in the ancestral area mostly on the inherited land from the father within their clan. This is the place where one would be interred. Any "house" built outside the ancestral land is not regarded as a "home" but a "house". This distinction between a "home" and a "house" is common among most ethnic communities in Kenya. See for example, Cohen D and Odhiambo A (1992): Burying SM: *The politics of knowledge and the sociology of power in Africa*. Portsmouth, New Hampshire: London; Heinemann; James Currey.

[15] Men are the only custodians of community land. Women have only user rights when they are married.

clans. Therefore if they died before getting married, they were buried far away from their homestead as "strangers". This was stigmatizing to the deceased and their families.

Given the cultural significance of land to their lives, the Abagusii believe that their land cannot be inherited or sold to outsiders. This is because the ancestral spirits which reside there will be displeased and cause harm to the family lineage. This makes members of the community to have a lot of spiritual attachment to their ancestral land. Due to this, it is mandatory for each community member to be buried in the ancestral land where he or she is a member.

**The social organization of everyday life**

The Abagusii everyday life is governed by a moral code of avoidance," *chinsoni*" (Masese, 2011; Levine *et al* 1998). The *chinsoni* code defines the everyday social behaviour by stipulating rules governing everyday actions, roles and functions of each member of the community. In doing so they define the "dos" and "don'ts" of each individual in everyday life and also how these definitions must be performed in order to enhance the functionality of the community at large.

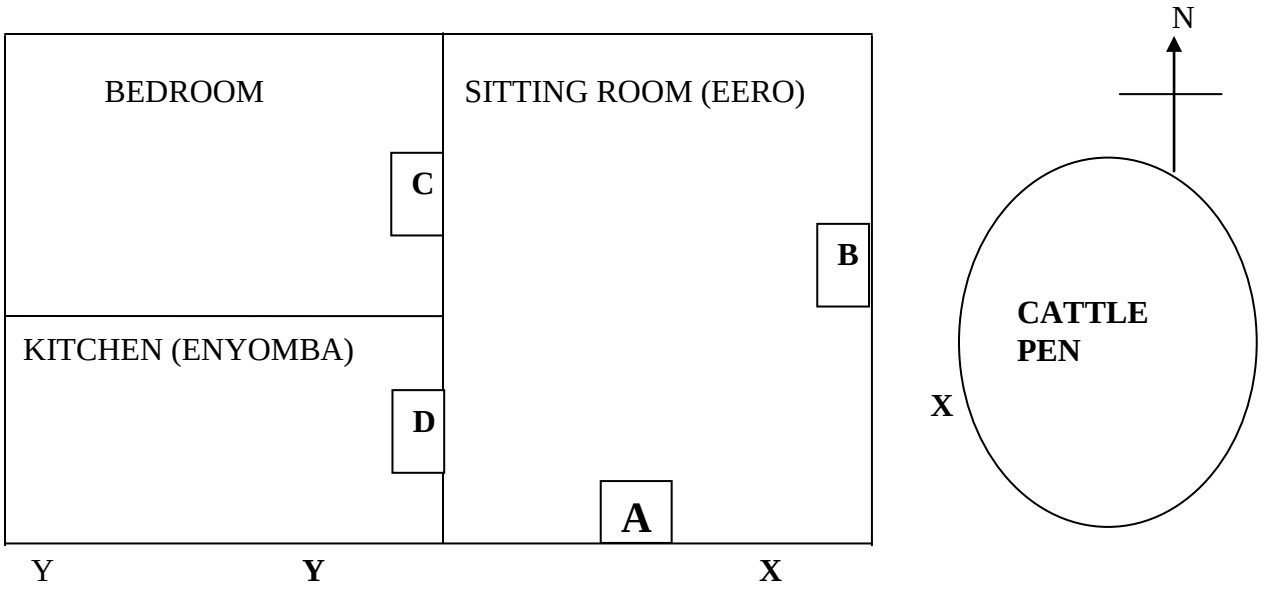
Learning of the *chinsoni* code is done at the family level through the process of socialization. This process starts almost immediately when a person is born and continues all through a person's lifetime. To ensure adherence to this code, there is a system of reward for those who conform, and punishment for those who deviate (Akama and Kadenyi, 2006).

At the family level, the C*hinsoni* stipulates a social ranking system where the father is ranked higher, followed by the mother, initiated sons and daughters respectively. This ranking defines the chain of authority especially in decision making. In this case, the father is the overall decision maker in the family and every member is required to conform to the decisions made by him. However, to avoid abuse of this hierarchical power, there were built in checks and balances.

As the overall decision maker, the father is expected to guide his family to meet the expectations of the community which in all cases transcended the everyday life. For example, though it was taboo for the Abagusii to plan for death prior to its occurrence, it was the duty of the father to ensure that his adult male children adhered to the cultural requirements which were mandatory in the performance of cultural death rituals which were key in the transition of the dead person's spirits to the level of ancestors. This cultural adherence first and foremost entailed ensuring that all adult sons built "a home" (which is symbolized by a house) on the inherited land where death rituals would be performed. It was also mandatory for the house to conform to the *chinsoni* code.

According to the *chinsoni* code, every house must have a sitting room (*eero*), sleeping room and fire place/kitchen room (*enyomba).* *Eero* is a place where the head of the house meets and entertains his friends; and where family rituals are performed. The kitchen/fire place room (*enyomba)* is the room where a woman spends most of her time either cooking for the family or meeting her visitors. Outside the entrance to *enyomba* is a yard where many routine family activities take place. Outside *eero* is the cattle pen (*obweri).* Enyomba as a woman's room is considered the left side of the house while *eero,* a man's room is the right side. This is the conceptual division of the house and adjusted places is illustrated in **Figure 3:1**

**Figure 3:1 Sketch of the Abagusii house**




**KEY**

A: MAIN DOOR

B: CATTLE PEN DOOR

C: BEDROOM DOOR

D: KITCHEN DOOR

X: BURIAL SITE FOR HEAD OF THE HOUSE

Y: BURIAL SITE FOR THE WIFE

To ensure compliance to the cultural standards of building a house, the avoidance principle of *chinsoni* demands that a father can only access his son's house through the cattle pen door and spends time in the sitting room only. Given the belief that when a father accesses his son's house and spends time at the sitting room brings with it abundant blessings to the son and his family, the son is forced to build his house according to the cultural standards. Both the cattle pen door and the sitting room play a key role during the death of the head of the household. For example, the remains of the head of the household lie in state in the sitting room awaiting burial, and it is only through the cattle pen door that his remains are removed for burial.

In addition, the prohibition of a father in law using the same door as a daughter in law ensures that there is a kitchen door for the latter to use. Further, the prohibition that women cannot sit in the sitting room when men are seated there chatting, demands that they have a fire place/kitchen room where they can sit and do their chores. The fireplace/kitchen room is later used as a place where the remains of the woman will lie in state awaiting burial while the kitchen door will be used to remove her remains for burial.

The concept of *chinsoni* also played a big role in the division of tasks both at the family and community level. Though in both levels the division of tasks was gendered, the *chinsoni* code stipulated which roles each community member could perform at either family or community levels especially those involving cultural rituals. For example, whereas it was mandatory for all men to participate in the performance of death rituals, their role was restricted to either family or clan level. At family level, men were required to participate fully in the performance of all death rituals involving their kinship member. These rituals were, but not limited to mortuary practices, interment and sacrifices. However, beyond the family their direct participation in death rituals was somehow restricted.

In everyday life, the *chinsoni* code defined the expected behaviour of both men and women in various contexts. In defining the expected behaviour, *chinsoni* code was premised on the fact that what men were supposed to do in a given context, women were not supposed to do it. In everyday discourse, this definition of expected behaviour is mostly constructed in the right and left hand dichotomy. The right hand is associated with men and reflects power whereas the left hand is for women and denotes weakness. In this case, men were expected to behave or act in a way which demonstrated power and control while women behaviours are to signify weakness and submissiveness. For example, showing of emotions openly was seen as a good feminine virtue among women but it was a weakness regardless of how grave the situation was among men.

Among the Abagusii, the *chinsoni* code acted as an apparatus of surveillance and control through what Foucault (1977) refers to "discipline". According to Foucault, "discipline"

is a form of social repression instituted by societies through discourses that seek to normalize certain practices while constructing others as repressive. This normalization is mostly rationalized by the values, taboos, rules and regulations governing everyday life as contained in the Abagusii culture. Consequently, the *chinsoni* code was more of an organizational catalyst which not only defined the expected behaviour of each community member but also defined how various functions could be performed at either family or community level.

**Conception of life and death**

The Abagusii value life and believe that *Engoro* (God) created and sustains life. To them life starts at birth and transcends past death. This does not imply that they never cared for the life of the unborn. Instead they believed that it is only at birth that an individual acquires specific status and identity as a member of the community. Before birth, mothers were supposed to observe various rules, taboos and norms as a way of protecting the unborn child from harm. Some of these rules, taboos and norms include the foods to avoid eating, the type of wild animals one should avoid getting in contact with and the tasks to be avoided, such as participating in the performance of death rituals.

The Abagusii believed in regeneration of life through birth of new members. Newborns were named after kinship members who had died a "good death" and also had good attributes in their lifetime (Gechiko, 2010). This was borne from the belief that the newborn child would acquire the same traits as the departed kin member whom she/he is named after. This meant that those who were perceived as deviants in the community or died from stigmatizing illnesses or committed suicide were not named after.

The belief in regeneration of life through social reproduction made the Abagusii to take concrete steps to ensure the survival of newborn members. According to Akama *et al* 2006, the belief that *Engoro* (God) is the giver of life necessitated mothers of newborns to dedicate caring of their newborns to *Engoro* by uttering immortalized words "*rioba nderere*" (the sun take care of my baby) every morning facing the rising sun (*erioba*)

carrying their children. The sun was perceived as *Engoro's big* eyes which could protect the newborns from any harm or misfortune.

In situations where there was high mortality rates of young infants, mothers of newborns were required to carry out some rituals called "*Ogotakera*" as a way of protecting the young ones from death. *Ogotakera* ritual involved placing the newborn baby at a common footpath in the village where passersby would spit on and throw leaves next to the child. These actions were meant to demean the value of the child as an "*unworthy to be selected by the hand of death*". The *Ogotakera* ritual was borne from the belief that death of young children was not natural but was caused by witchcraft. Therefore, by spiting or throwing leaves next to the child, made witches to see the child as valueless and unworthy of being harmed or killed (Masese, 2006).

Children who had undergone the *Ogotakera* ritual were not named after their departed kinship members. Instead they took names which were considered as undignified such as 'Nyanchera' for girls and 'Makori' for boys which literally meant 'footpaths'. Other names were Nyangau (Hyena), Basweti (Python) and Ntabo (a fruit from an inedible thorn tree *Solanum indicanum* spp) among others. The use of these undignified names was meant to devalue the worthiness of these children in the eyes of witches or evil spirits.

Other methods of preventing child mortality centered on nullifying the power of witchcraft and evil spirits using magical antidotes. These magical antidotes involved either putting magical amulets "*erinsi*" or applying some magical solutions either internally or externally to the child's body with the believe that they could protect the child from any harm (Matsuzono,1993).

These measures taken to prevent child mortality are a reflection of the central role of motherhood and fatherhood in the community. It is only through it that a man or woman acquired the cherished self identity as a person. Consequently, those without children were stigmatized and when they died, their deaths were classified as "bad deaths" because they left no one to carry on their lineage.

Though all children were valued among the Abagusii, a male child was most valued. This valuation started immediately after birth and continued beyond lifetime. At birth, a boy child was welcomed into the world by at least four ululations by the midwives, while a girl child with only two ululations. This symbolized that a boy child was of higher status and value than the girl child (Masese, 2011).

In addition, at birth a boy child was seen as belonging to the *egesaku* (cattle pen) while a girl child belonged to *ense* (the world) (Mayer, 1975). This differentiation meant that a girl was considered as an outsider to the patrilineage while a boy was seen as an insider as symbolized by the cattle pen. As an outsider, a girl was not regarded as a full member of her natal home (lacked proper identity and status) and she was expected to move out of her natal home (get married) once she becomes an adult in order to get proper identity and status.

The status of a girl as an outsider was also affirmed in rituals and jural norms (Hankson, 1994). In funerals, for example, both married and unmarried girls were allowed to play peripheral roles equivalent to that of distant kins or affines. This is because among the Abagusii, funeral arrangements are done by the nuclear patrilineal group and those considered as outsiders are not involved so much. Also if an unmarried woman died at her natal home, she is buried far away from the homestead because it was a norm for outsiders not to be buried within the homestead (LeVine, 1982).

After birth, the newborn underwent through infancy period which lasted for two to three years. In the first six months, the greatest amount of attention was paid to the needs of the newborn to ensure its health and survival. This was achieved by the mother taking preventive measures to protect the infant from illness and "evil eyes" (*ebibiriri*[16]).
After infancy, the child was weaned "*ogotacha",* which literary means to stamp or step on, by not only stopping the child from suckling but also socializing the child to the

[16] For further reading on *ebibiriri* (evil eyes) see Matsuzono M (1993): Rubbing off the dirt: evil-eye belief among the Gusii. *Nilo-Ethiopian Studies* 1: 1-13 (1993)

expected gender roles and behaviour. In this regard, boys and girls were trained on what it means to be a" man" or "woman" respectively in terms of the tasks to perform and the dos and don'ts in daily life. Conformity to specific gender roles and behaviour was rewarded and non-conformity punished.

The socialized gender roles and behaviour were further instilled during circumcision rituals which marked a passage to adulthood. These rituals were gender specific and instilled the value of *omosacha* (man) and *omokungu* (woman) through the many ordeals initiates underwent. According to Masese (2011), the importance of these ordeals can be appreciated through the socio-cultural principles of death and rebirth, and that of establishing a covenant.

In the principle of death and rebirth, it was recognized that before circumcision the initiate was not fit to join the adult world. To do so, the pre-circumcised personality had to be dismantled and a new one constructed. For this to happen, death of the former personality must happen through pain. Consequently the initiates underwent painful ordeals to test their perseverance, courage, independence and decision making abilities before they were circumcised. These ordeals were meant to destroy or dismantle the old status through "death" and reconstruct new status or personality during the seclusion period. In seclusion, the initiates were taught the expected social roles and behaviour. The painful ordeals were assumed to make them value and cherish their new status because they endured a lot to achieve it.

The concept of death and rebirth is signified by the surgical operation which targets the body organs that help in generating life. Given the fact that genitals are used as a means of perpetuating life, they are targeted during circumcision where some parts of it which symbolize pre-adulthood status are surgically removed ( destroyed through death) to pave way for regeneration of the new form (rebirth) which symbolizes adulthood. This death and rebirth of new status is clearly expressed in circumcision songs "*esimbore*". For example among the boys the song went like; *Samokami oirire 'mboro chiato* (circumciser has taken our penises).....*mbooro chiato indokore rekonoire*.... (Our penis is like a green

tree with its bark peeled off- a new and better one comes). This transition from childhood to adulthood was also appreciated in girls' circumcision songs..... *omokebi oirire ebisono biato* (The circumciser has taken our clitoris).....*orenge mokabaisia.... obeire mokabamura* (she was wife to the uncircumcised boys.... she is now a wife to men).

The shedding of blood during circumcision also symbolized making of a covenant which bound the initiates to abide by the rules, norms and values of adulthood. In addition, they were supposed to follow the community traditions and live as per the expectations of the community (Masese 2011; Monyenye, 2006).

The important role of circumcision is that it prepared initiates for marriage and procreation. This was achieved through the various rituals the initiates underwent. These rituals were mostly symbolic but emphasized the need of the initiate to engage in social reproduction. This was important because this not only helped in the regeneration of the community but also enabled the initiate to attain the desired social identity and status. Those who underwent circumcision rites and never engaged in social reproduction were despised and stigmatized as evidenced in the following song:

| ***Ekegusii*** | ***English translation*** |
|---|---|
| Solo: *Mosaiga Siberia on'ge* | Comrade sip and pass over to me |
| Chorus: *Toa monto ogosiema nyaro* | Do not give to one who points underneath |
| | |
| Solo: *Nyakoibora omo, oraiyaa* | You who gave birth to only one child, raiyaa |
| Chorus: *Arari/warari Ara*i | *Arari/warari Ara*i |
| Solo: *Otare koibora bange oraiyaa* | You should have given birth to many, raiyaa |

In this song, the phrase "*ogesiema nyaro*"(points underneath) refers to sexual impotence which is denoted by failure to sire children. As a consequence the person was socially isolated by other community members. This is why immediately after circumcision the initiates were given some traditional grass " *ekerundu*" (Malva verticillata), a symbol of fertility, to held on the hand as they were taken for seclusion. Though social reproduction

was the function of both men and women, most rituals gave more prominence to male roles due to the patrilineal nature of the community. Consequently, the importance of social reproduction was signified by the rituals before, during and after seclusion.

Before seclusion, male initiates were required to pass in between the cattle kraal and the main door leading to the mother's house which was surrounded by male members of the father's lineage. As the initiate passed through there, the father sprinkled sour milk on him as a symbol of blessing to bear many children and acquire abundant cattle. After seclusion, the initiate was required to visit his parents' house for the first time to receive "*special blessings*". During this visit, the parents were required to lie on their sleeping bed having or pretending to have sex. As the initiate entered the house through the kraal pen door "*Egesieri kia bweri"* he would announce his presence by uttering a standard statement requesting his parents to bless him with *special blessing* as follows: "*Tata na Baba borania ango?*" (Literally translated, please father and mother talk with each other and give me blessings). After this, the father and mother will respond in turns as ""*Ee mwana one borania chiombe na abanto"* (Yes, my child, have the blessings of many cattle and children).This response by the parents while having or pretending to have sex implied their blessings for their son to own abundant wealth (symbolized by cattle) and most important have successful sex life which is signified by procreation of many children (Masese, 2011).

During seclusion period, the initiate was preoccupied with tending to sacred fire. This fire was lit at the start of seclusion and was not supposed to go off until seclusion period is over. This fire was lit by rubbing dried hardwood stick with softwood that was laid horizontally across the floor. Using both palms, the hardwood stick was vigorously rubbed against the grooved softwood stick until sparks of fire were produced. This fire sparks were then used to make the sacred fire.

The hardwood stick which was rubbed vertically is known as "*ekerende egetwoni*"(male stick) and the softwood one which lies horizontally on the floor was the "*ekerende egekungu*" (female stick). The two sticks symbolized a man and a woman engaging in

coitus act (rubbing of the sticks against each other) to produce a child (signified by the fire). This therefore means the making and taking care of sacred fire symbolized the central role of social reproduction in adult life and thus it must be guarded and taken care of at all costs.

Circumcision was important in preparing initiates on their social roles as a man or woman in a family setting. This was made possible through the various rituals the initiates were made to go through during the seclusion period. For example, at the onset of seclusion period, all initiates were supposed to plant *esuguta* ( Pennisetum catabasis spp) within the seclusion house. They were required to ensure the grass remained ever green throughout the seclusion period by watering it continuously. This symbolized physical health in adult life which is brought through cultivation of crops. This symbolism is brought out clearly through the ritual song the initiates sang while watering the *esuguta.* The song underscored the importance of tilling land and growing of crops which enabled a person to have many friends through sharing of food. The song was as follows:

| ***Ekegusii*** | **English** |
|---|---|
| *Ya nyasuguta abare sabarie* | Of drop grass initiates |
| *Makomoke oremire 'nchera igoro* | Aunt has dug (cultivated) on the wayside |
| *Akwanigwe na moeti na mogendi* | she may be greeted by passersby.& travellers |
| *Akwanigwe n'onde otaitongo* | she may be greeted by even the seated ones |
| *Imboremo bwaborire* | is there scarcity of land |
| *Tiga areme* | Let her cultivate/dig |

The values of circumcision were very important for initiates as they entered adult life. All the teachings they got were supposed to guide them in all their life. The initiates were never expected to regress to their childhood behaviour. To ensure this, initiates especially the male were not allowed to interact freely with uninitiated boys. The initiates were firmly instructed to shoot the uninitiated boys with their blunt arrows whenever they encountered them. This was to create fear among the uninitiated boys thus reinforcing the social distance with the initiate. Throughout the seclusion period, the male initiate was

made to live a life totally different from that he lived prior to circumcision. He was to learn to be self-reliant and independent.

On the other hand, girls were not trained to be self-reliant and independent during circumcision rites. During seclusion, the girls were under the custodian of their mothers who trained them on their future married life. To achieve this, the mothers assigned the initiated girls many duties they were expected to perform in their houses after marriage. Initiation for girls therefore, prepared them for marriage and the sexual adult life. While the boys' initiation ceremonies emphasized a training for bravery, leadership, independence and self-reliance

Circumcision rites among the Abagusii have undergone various changes in response to socio-economic changes (Rianga, 2007). These include the abolition of girl circumcision and replacing it with "ritual without cut", replacement of cultural rituals with christianity rituals and drastic reduction of circumcision age from 13 to 6 years. Despite these changes, the values associated with circumcision are still strongly held by community members.

Apart from circumcision, marriage is an important rite of passage in a person's life. It not only ensures continuity of the lineage, but also accords the young people an opportunity to attain adulthood, access to family resources and identity. Thus, those who died before marrying were stigmatized (Shadle, 2006). Marriage was between members of different clans with the woman moving from her natal clan to go and stay with her husband in his clan. It was a taboo for members of the same clan to marry each other as they were assumed to be related to each other due to their common ancestry.

Marriage was established through payment of bride wealth by the husband's family to the wife's family. Payment of bride wealth was essential in solemnizing marriage and gave the man social paternity to all children the wife gives birth to irrespective of their biological paternity. It also gave the man social power to control the wife's social life.

Similarly, bride wealth also accorded a woman a recognized status in her natal home as well as getting assimilated to the man's lineage as a wife and mother (Hakansson, 1994).

In marriage, children were very important. If a woman died without children, the widower could legitimately demand return of his entire bride wealth. In a woman's lifetime, her attribute as a successful wife was linked to bearing children (Shadle, 2006). Although all children were important for making marriage a success, sons were the most preferred. Sons were essential for a man's future as they preserved his memory and ensured social status and identity among peers. Women also attained their security in marriage via their sons as demonstrated in these two Gusii sayings; *"ensinyo ekoramwa mbamura etabwati"* literally translated as the place which is despised is the one with no sons. "*Omorogi omwenenu no'oyore na abamura"* literally translated as a witch who is rude is the one with sons. Witchcraft was normally associated with women and was distasted. In this case "a witch" symbolizes a bad woman who does not care about her deeds or behaviour because she has sons to protect her.

The premium of social reproduction was evidenced through rituals which followed immediately after solemnization of marriage and payment of bride wealth. These rituals entailed the mother in-law preparing traditional food at her home and giving the sisters or cousins of the married daughter to take it to their in-laws lineage members to eat. The son in-law was not allowed to eat this food. The sisters or cousins were not restricted by the moral code of avoidance and they were therefore required to spy from their married kin the sexual potency and prowess of their new brother in-law.

Sexual potency and prowess was construed as an indicator of the ability to engage in social reproduction effectively. The information got was supposed to be shared in confidence with the mother who would later share it with the father for decision making regarding the future status of that marriage. In case the sexual potency and prowess of the son in-law was found to be questionable, the mother would refuse to prepare another set of traditional food to be taken to her in-laws to eat. This refusal was enough communication that the marriage should be dissolved because of the inability of the man

to engage in social reproduction effectively. However, where the man's potency and prowess is good, the mother-in-law would prepare another set of traditional food to be taken to the in-laws lineage members. As a sign of approval and acceptance from the mother-in-law, the son-in-law was allowed to eat this food.

In contemporary Gusii, marriage has undergone drastic changes. Initially cattle were used as a mode of payment of bride wealth. However, this has been replaced by cash payment though the amount to be paid is calculated equivalent to number of cows to be paid (.Nyamongo, 1998). Hakansson (1994) also observes that unlike in the past, young people are nowadays in the forefront of making their own marriage arrangements without involving their parents. Traditional marriage ceremonies have also been replaced by religious and civil ceremonies; and elopement and cohabitation are common and are recognized as part of the marriage process awaiting solemnization through payment of bride wealth.

Despite these changes in marriage, the traditional values and principles governing it are still intact and observed. Marriage still remains the only conventional means of attaining and affirming adulthood status. Solemnization of marriage is only through payment of bride wealth and procreation of children is mandatory not only for regeneration of the community but also accords both man and woman proper social identity and status.

The last rite of passage of personhood is death. Among the Abagusii death is seen as the beginning of a process through which a dead person transits to become an ancestor. This transition is believed to be through three fundamental stages. The first stage involves separation of the spirit of a person from the body as well as from social obligations. When this occurs, the person is then defined as dead. After this, the spirit is believed to enter a liminal period. In this stage, the spirit is undefined as either a member of the living community or part of the community of the dead. Culturally, it is believed that at this stage, the spirit is most vulnerable to itself and to the living members, depending on how it is treated by the living community members. Finally, the spirit is incorporated into

the ancestral community where it is given a new role within the society of the living community members.

Though death is perceived as a rite of passage which every human being must meet, it is nevertheless construed as unnatural. This construction is best appreciated through myths explaining the origin of death in the community. As observed by Paul (1996), myths provide an authoritative foundation for the continual construction, maintenance and reproduction of an ongoing social order. In Gusii mythical narratives, death is associated with jealous emotions which were first experienced within a family setting. According to this myth, a long time ago, people used to die, stay in the grave and resurrect on the third day. In one polygamous household, one of the wives died. The husband instructed the surviving wife to stay at home and nurse the dead wife when she resurrects. However, when the living wife saw the grave bulging to surrender the dead wife to life, she struck the grave with wood saying *motienyi okwa oboka na monto akwa asira,* (Literally translation: Moon dies and resurrects; a human dies and perishes). With this, the deceased wife sunk back into eternal death. Since then, human beings have continued to die and perish.

According to this myth, death is traced to jealousy among very close members of the same lineage. Jealousy is the emotion behind practices of witchcraft. Therefore, any death which occurs is as a result of witchcraft and is mostly expressed in everyday life by the metaphor "Ya*nya gokwa etaberegeti egotonga*" which is literary translated as "it never died on its own will". This means even if a person dies of a known cause, his/her death must have been influenced by malevolent forces (witchcraft).

The association of death with witchcraft does not mean that it is the only causation. In reality the Abagusii also believe in natural causation of death. However, the determination of the exact cause of death is influenced by the prevailing context of when and how it occurred. This means that the doctrine of witchcraft is not used to make sense of every death. For example, where an individual failed to use common sense or take known precautions to avoid death, such death is not attributed to witchcraft.

The plurality of the cause of death is best understood by examining the health seeking behaviour in the community. Among the Abagusii, illness was first conceived as a natural occurrence. The standard response was to seek treatment. However, if the illness continued despite the treatment taken, it was construed as unnatural. This necessitated close kinship members to consult traditional doctors (magicians) to determine the cause of the illness. This determination of the cause influenced the subsequent sick role and health seeking behaviour. In case death occurred at this stage despite all these efforts, such death was believed to have been caused by witchcraft.

Despite the belief in the plurality of the causes of death, it is common for the Abagusii to seek meaning of death whenever it occurs. This entails seeking explanations as to why death occurred the way it did to any member of the community. Such explanations are mostly linked to the prevailing social contexts preceding its occurrence. For example, even if a person died of a very well known medical condition such as HIV/AIDS, such a condition is not taken as the cause of his/her death. Instead the community members will try to deconstruct why he/she was infected in the first place. This deconstruction is done by examining the social relationship between the victim and other members of his/her social network. If the social relationship is found to be frost with any member of the social network preceding his/her illness, such a member is blamed as having influenced the infection using malevolent forces. This makes death to be more of a social than a natural fact.

As a social fact, death has profound influence on people's social behaviour. This influence is due to the construction of death as a transitional rite of passage to the afterlife. As a transitional rite of passage, the living members of the community engage in various rituals to aid the deceased to successfully transit to the afterlife. However, this engagement depends on whether such a death is seen as either a "good" or a "bad" death.

Death is constructed as either "good" or "bad" based on the normative cultural expectations of an individual's life project and the perceived cause of death. Normatively in the community, every person is expected to die at a ripe old age after undergoing

circumcision and having children especially sons in a formal marriage. Whereas old age and undergoing circumcision are equally important determinants of "good" death, more emphasis is on having children, especially sons in a formal family setting. This makes dying without a son(s) a "bad" death. Dying without a son is mostly expressed either by "he/she died completely" or "he/she did not have anyone to bury him/her" metaphors. These metaphors denote extinction of one's lineage and non-belongingness in kinship relations.

On the other hand, death is construed as "bad" when its cause is socially seen as "unnatural". "Unnatural" death in this context denotes two aspects which are mutually exclusive. One, is when a person is solely responsible for taking his/her life; two, when death occurs as result of natural phenomena such as lightening and floods or none observance of social and moral norms governing sexuality.

In making sense of the type of death, both the normative cultural expectations of individual life project and the perceived causes of death are used concurrently. For example, if a person has met all the cultural life project expectations but dies of a stigmatizing illness, such a death is still construed as a "bad" death. However, given the fact that "bad" death is not associated with the afterlife, such deaths are managed by close kinship members of the deceased through the culture of denial and concealment largely due to fear of social stigmatization, ostracism and isolation by the larger community.

As observed earlier in this chapter, death among the Abagusii is seen as a transitional process to the afterlife. For this transition to be successful, a number of rituals which incorporate the corpse are performed. These rituals not only aid the dead person's spirit to transit to the afterlife but also affirm the dead person's power and status in his/her lifetime; and the society's power over death. However, the performance of these rituals is relative to the type of death (good or bad), gender, age and social status of the deceased (Levine , 1975).

Death rituals conventionally start immediately after death. However, initial preparations start at one's lifetime especially after one has undergone circumcision. For example, each adult male was supposed to build his own house in conformity with "*chinsoni principle*", get married and have children. Building one's own home is very important because it acts as a space for performing death rituals when one dies. For those who died without building their own house, a small structure called *egesamo*[17] was built to represent a house for purposes of performing death rituals. Similarly, those who died before marrying or having children were stigmatized, and no death rituals were performed on them. This makes preparation for one's death an everyday lifetime event even though it's not openly discussed or acknowledged.

Death rituals in the community are not only a means of dealing with death as a social and personal disruption, but are also performances defining the ultimate meaning of life. This is in line with Hertz (1990) observation that to understand the meaning of life and death in many cultures is to make sense of death rituals. Consequently among the Abagusii death rituals take place in the home of the deceased. Each action from dying to posthumous sacrifices has a customary space/location regarded by the Abagusii as an essential part of the ritual. In this case each ritual was performed within a specific space/location within the house which the deceased lived in his/her life time. For example, each house (**see Figure 3:1**) had a kitchen (*enyomba)*, sitting room *(eero)* and bedroom.

During the dying process a man was removed from the bedroom and placed in the sitting room (*eero)* to die. His remains were buried on the right hand side of the house symbolizing his power and status as head of the household. On the other hand, a woman was supposed to die in the kitchen (*enyomba)* and her remains buried on the left side of the house symbolizing her subordinate position. In case death occurred outside the house, it was mandatory for the remains to be brought into the house to lie in state for at least a night in gender specific rooms before being buried in gender specific locations.

[17] *Egesamo* is a small temporary house built for a "houseless" person for burial rites only. A houseless person in this context is any person who has not built a house on the inherited land from his father. In every day discourse *egasamo* is a social representation of low social status or failure to attain adulthood status.

In addition, each adult person had a unique location for burial, one that was not shared with any adult member of the same sex. This is because each person had individual social identity which needed protection and preservation. This is in spite of the fact that corporate identity of the homestead and the generational continuity of the lineage is emphasized during the funeral. Hence, it was mandatory for each married man to have a house which he built for himself, and a woman a house in which she cooked as a wife. The salience of this rule is reflected by the fear of young men and women that they might die without having a house of their own. This acts as a motivation for young men to build a house in their ancestral home even if it is not of immediate use and women to get married as a way of securing a place for a decent burial[18].

In contemporary Gusii society, adherence to these spatial ideals is taken serious regardless of the cost involved[19]. They take pain to assure proper placement of their own bodies and those of their kin in death and burial. This is to ensure the dead person is reunited with his /her ancestors in the afterlife. Failure of this reunion taking place means that the dead person's spirits will remain in liminal state where it will cause problems to the living members.

[18] Young married men who die without their own house were buried outside *egasamo* which was demeaning and stigmatizing. Unmarried women who died were buried to the left side of their mother's house but far away from the homestead. The left position reflected her gender and the distance, her status as someone who ought to have left home and died at her husband's homestead.

[19] The Abagusii spend colossal sums of money to transport their dead to their ancestral home for burial regardless of where the death occurred. This cost is not only restricted to transportation but sometimes it involves litigation costs especially when there is conflict between the nuclear and the extended family on the site of burial.. See for example: Elvis Ondieki (2016): "Shock as mourners attend funeral of man already buried" available at: http://nairobinews.nation.co.ke/news/48052/ Accessed on 15 April 2016.

After death, the body is removed from the house through the gender specific door and buried in the gender specific site (refer to earlier discussion). The digging of the grave starts at the break of sunrise and the preferred person to break the earth first for the grave was either the eldest son or grandson[20].This was important as it symbolized continuity of the deceased's lineage and confirmation of proper social identity and status which is attained through social reproduction. This symbolism is best captured by the metaphor, "*you need a son to bury you*".

In digging the grave, men whose wives were pregnant were not allowed. This was meant to protect the unborn child from harm. Pregnant women and their husbands were also prohibited from touching the earth of the grave even after it has been filled. This prohibition was also enforced during throwing of the first handful soil unto the grave when the body has been lowered.

Throwing of the first handful soil into the grave was done first by either the son or the grandson who were also the first ones to break the earth of the grave. This was followed by other close agnates and the wife[21] of the deceased. This act was meant to beseech the deceased to continue blessing and interceding for them favorably as he moves to the ancestral world. Once this ritual is done, the grave diggers filled the grave with soil. After this, an uncircumcised girl brings them water which she had fetched from the river to wash the soil from their legs and hands before leaving. In bringing this water from the river, the girl was not supposed to look back or sideways until after delivering it at the gravesite.

These rituals which followed the filling of the grave symbolized regeneration of life and triumph over death. The river in this context symbolizes the source of life. The action of

[20] Payment of bride wealth gave a man social paternity to all children the wife gives births to regardless of their biological paternity. However, during death rituals biological paternity is a primary consideration for participating in death rituals. This is because biological children share the same blood with the deceased and other kinship members, an important aspect of lineage continuation. This dichotomy of "biological" and "social" paternity does not disqualify the latter from being considered as children of the deceased at the time of death and even after.

[21] In case the wife had committed adultery in the course of her marriage, she will refuse to throw the first soil to the grave for fear of attracting harm to herself and her children.

fetching water by an uncircumcised girl meant that even though one's life has ended through death, a new life will be born. The uncircumcised girl in this case is a social representation of an unexploited fertility given the fact that she will engage in social reproduction once she is circumcised. The action by the uncircumcised girl not to look back or around after fetching water is supposed to scorn at death as not worthy, as new life is on the offing. This was climaxed by the washing of the soil from the feet and legs of the grave diggers at the graveside which symbolized triumph over death.

After burial, the widow was supposed to put on one of her husband's clothes inside-out *ogokobania* to signify her sorrow and affirm that she will continue perpetuating the husband's lineage. After this the exterior roof stick of main house *egechuri* (if it is a grass thatched house) or small section of iron sheet is removed from the roof to symbolize the end of male authority over the woman of that house.

In the evening after burial, a cock was slaughtered and eaten by close agnates only as a confirmation that the head of the household is no more. This was not the case for women. A goat was also slaughtered as a sacrifice "to cool the house" (*embori yogokendia enyomba*). This was done to placate the deceased so that his anger about his death will not result in affliction to the living members. The goat sacrificed was of the same sex as the deceased.

The day after burial the community organized a public gathering "*eburu" to* mourn the dead. A large number of people would come to pay their last respects to the dead. In older days the deceased's cattle were driven over the grave by community members performing a mock fight with invisible enemies. This mock fight was to demonstrate their resilience and triumph over death. The close agnates to the deceased were also required to shave their hair at the graveside as a sign of starting a new life minus the deceased. After this some personal possessions of the deceased like his sitting stool or a woman's cooking utensils were turned upside down "*ogotureka chingambo"* to usher in the official mourning period. In the evening another goat was sacrificed "*embori yamatoronge*" (goat for portions). The meat of this goat was distributed to close kinship members to take to

their houses to cook. Metaphorically, this meant that they were free to go and resume their everyday activities.

After sometime, another sacrifice *okogororokia chingambo* was performed. This was meant to normalize life in the homestead by symbolically reinventing all inverted personal possessions of the deceased to normal positions and fixing back the exterior roof stick of main house. This is the last sacrifice in the deceased house. Another subsequent sacrifice was performed at each married son's house, called *okorenta omogaka/omongina nyomba* "bringing the patriarch/matriarch into the house". This sacrifice was meant to protect each son and his immediate family from any potential ill of the dead person's spirits. Later, each of the married paternal grandsons had to do the same: "bringing grandfather/ mother into the house" (*korenta sokoro/magokoro nyomba*). When this was done, the spirit of the dead is placated by every house in the homestead. This is the last death ritual and it was expected that the placated spirit will protect the living in its afterlife.

The above rituals were, however, not performed to those who died "a bad death". Instead rituals which were performed aimed at preventing such deaths to recur. For example, it was considered a curse for the family if a young circumcised man of marriageable age died without a wife. To prevent tragedy befalling the family, the bachelor was buried with a piece of wood by his side "*korutwa omware"* symbolizing a fulfillment of marital and reproductive goals that was never attained. Similarly, if a young woman of marriage age died without having children, her nibbles were pierced with a thorn. This symbolized that her nibbles were never suckled and therefore none should mourn her death. Instead, a small chick was tied next to her grave "as the only thing which could mourn her".

Killing one self or suicide was constructed as "a bad death". Those who committed suicide were neither mourned nor named after. This was to prevent such a death from happening again. Instead sacrifices were performed to ward off the spirits of that dead person from influencing another person to do so. This was done by strangling a sheep on the same spot where the person performed the act. The sheep must be of same sex as the

victim. As the sheep is being strangled, the body of the deceased is let loose to fall into the ground. On the ground, the body was then covered with soil on same spot where it fell as no one was supposed to touch it. The tree which was used to commit suicide was uprooted and burned.

Death from a stigmatizing illness especially those associated with non-observance of sexual taboos was also classified as “bad death”. In everyday life, such deaths were seen as equivalent of “killing one's self” because they arose from either omission or commission by the individual in relation to the expected sexual behaviour. Such deaths were not mourned and the deceased was not named after.

As a community, Gusii has witnessed profound socio-economic and political changes. These changes have ushered in new norms and values which have greatly affected how people deal with death. For example, change from traditional religious system to Christianity has impacted death rites through social transformation of notions of personhood, death and afterlife. Similarly, technological changes have ushered in new material culture of death such as wearing of printed T-shirts with images of the deceased by close agnates as a means of marking group affiliation. Paradoxically, the community has managed to enclose itself in its own moral and value system, deeply embedded in rigid norms, rules, taboos and ancient traditions governing death. So, in modern Gusii land, it is not common to see new and old forces coexisting in relation to death. This interplay is more pronounced when dealing with HIV/AIDS death due its construction as “a bad death” as discussed in **chapter five.**

**Summary and conclusion**

The Abagusii way of life is best summarized by the everyday social representation of their life in relation with the land they live in (*riroba*). *Riroba* which means "the soil" is not only perceived as "immortal” but a generator and consumer of life. As a generator of life, it is a medium on which all people meet their livelihood but also constitutes relations with both the living and dead through kinship and other forms of substantial relatedness that link one person with others. Consequently, everyday life is governed by social

values, norms, rules, regulations and taboos whose sole purpose is to generate and regenerate life. However, just as *riroba* weathers due constant use and climatic changes, the Abagusii way of life is also undergoing drastic changes due to socio-economic changes which in most cases have led to the "reinvention of traditions" (Hobsbawm *et al* 1983) in all aspects of their daily lives.

# CHAPTER FOUR

## RESEARCH METHODOLOGY

### Introduction

The choice of a particular method of social research depends *inter alia* on the nature of the research problem, the data needed and political factors such as institutional and legal practices guiding research in a particular context. These issues determine who to study, how to study, how and which knowledge to use. In particular, this chapter explores the methodological processes and practices which informed the present study on the socio-cultural meanings of death from HIV/AIDS and its influence on HIV/AIDS prevention of HIV among the Abagusii community, Kenya. Throughout the chapter, I show how social construction ontology and interpretative phenomenological approach shape the study. Further, the chapter discusses the challenges of maintaining a critical distance as an emic anthropological researcher investigating a sensitive topic of death and HIV/AIDS illness.

### Research Site Description

This study was carried out in Mosocho division, Kisii County for a period of one year and three months. Mosocho division is situated in Kisii Central, a sub-County of Kisii County. Kisii County is one of the 47 Counties in Kenya. It is located to the South-East of Lake Victoria and is bordered by six Counties with Narok to the South, Migori to the West, Homa Bay to the Northwest, and Kisumu to the north, Bomet to the South-east and Nyamira to the East. Mosocho division is located about 15km from Kisii Town.

According to the 2009 National Census[22], Kisii County District had 1,152282 people comprising 5550464 males and 597236 females. With a population growth of 2.1%, the population is estimated to be 1,362779 with 650,982 males and 711,797 females (Republic of Kenya, 2010). Mosocho Division, the site of this study has an estimated population of 156,321 with 75,937 males and 80,384 females.

[22] This is the most recent national census. In Kenya, national census is periodically done after every ten years.

Mosocho division was purposively chosen, because since the advent of HIV/AIDS in Kenya, the division has continued to report high prevalence rates of HIV/AIDS. This has been attributed to high poverty levels of 59.8% which is way above the national poverty level of 46%. As a consequence, most people are forced to engage in risky sexual behaviour as means of meeting their everyday sustenance. For example, due to poverty most men are unable to provide for their families as per the cultural division of tasks. As a result, a number of them engage in widow sexual cleansing practices in the neighboring Homa Bay County which is inhabited by the Luo community for pay. This has contributed to high HIV infection rates in the division.

Widow sexual cleansing which is known as "*chode kode*" among the Luo is a practice where widows are expected to engage in sexual cleansing with a "cleanser" without a condom in order to remove the impurity ascribed to her after the death of her husband (Perry *et al* 2014). However, due to the stigma associated with being a sexual "cleanser" among the Luos, men from outside the community are hired to fulfill this cultural obligation. Given, the high levels of poverty and being one of the divisions bordering the Luo community, indulging in sexual cleansing is seen as a means of meeting livelihood despite its inherent risk of contracting and spreading HIV/AIDS.

Mosocho division has two health centres namely Iranda and Raganga. These two health facilities provide comprehensive HIV treatment for those affected or infected by HIV/AIDS. However, due the stigma associated with HIV/AIDS the local inhabitants rarely use these facilities for HIV/AIDS related services. Instead most people prefer procuring such services from neighboring Karachuonyo Division in Homa Bay County. Most users of HIV/AIDS treatment services in these two facilities are mostly outsiders especially from Homa Bay County. This health seeking behaviour is due to high levels of stigma. In addition, the high levels of poverty which increases people's vulnerability to HIV/AIDS risk makes this study site ideal for investigating the socio-cultural meanings of death from HIV/AIDS and how it influences HIV prevention.

**Research Design**

This study was concerned with the emic understanding of death from HIV/AIDS and how it influences prevention of HIV among the Abagusii-Kenya. In particular the study was concerned with socio-cultural meanings of death from HIV/AIDS, understanding the lived experiences of dying from HIV/AIDS and how these experiences and socio-cultural meanings of death from HIV/AIDS influenced action towards the illness from the cultural perspective of the Abagusii people in Kenya. To attain this, the study was more focused on understanding the socio-cultural meanings of death from HIV/AIDS and interpreting these meanings in relation to the lived experiences of HIV/AIDS illness. This therefore called for direct involvement of the researcher with the Abagusii people in their cultural context for an extended period of time. This was crucial in understanding the detailed description and context dependent interpretation of the socio-cultural meanings of death from HIV/AIDS and how they influence prevention of HIV. This study thus adopted an ethnographic research approach ( Copans, 1998; Geetz, 1973).

**Selection of research participants**

The selection of research participants for this study was influenced by three interrelated factors: First, the sensitive nature of the study. HIV/AIDS is a stigmatized illness which is mostly transmitted through unprotected sexual intercourse. This makes the disease to be associated with people who are sexually immoral. This moralization makes the disease to be a symbol of pollution and social contamination-a metaphor of evil. As a consequence most people do not prefer to be associated or linked with the disease because of the potential social risk or cost. Thus, in everyday life, the disease is surrounded by silence, secrecy, stigma and discrimination. Equally, in most communities in Sub Saharan Africa, death is a tabooed topic to be discussed in public. All these factors make this study very sensitive because it not only deals with a stigmatized illness but also a tabooed topic.

Two, in Kenya HIV/AIDS is mostly treated as a human right issue where individual rights, freedom and responsibilities are defined as per HIV and AIDS prevention and control act 14 of 2006. For example, section 22 of the Act prohibits the disclosure of

information concerning the results of a HIV test or any related assessment to any person except;

a) with written consent of that person,
b) if that person has died, with written consent of that person's partner, personal representative, administrator or executor,
c) if that person is a child , with written consent of a parent or legal guardian of that child,
d) If that person is unable to give written consent, with the oral consent of that person or with written consent of the person with power of the Attorney for that person.

Further, under section 23, Breach of Confidentiality is an offence punishable under section 42 by imprisonment for a term not exceeding 2 years or a fine not exceeding Kshs. 100,000/= or both.

The governance of HIV/AIDS as per this Act made the selection of research participants in HIV/AIDS research problematic especially those who were HIV positive. For example, how do you identify a HIV seropositive person without breaching section 22 of the Act given the fact that HIV/AIDS is surrounded by silence and secrecy due to potential social risks or cost associated with self disclosure?

Three, the focus of the study which was on the socio-cultural meaning of death from HIV/AIDS and how it influences HIV prevention meant that the study was an inductive research which was shaped by social construction ontology. This was accompanied by an interpretative epistemological approach which was more concerned with how interpretation of research participants' responses about death from HIV/AIDS influenced their actions towards the illness in their cultural context.

Considering these three factors, this study was thus a qualitative research. This meant that the study was more concerned with an in-depth understanding of the phenomena under study than making a generalization. To achieve this, the study took into account the

diversities that existed within the study population when deciding on the sample size as recommended by qualitative researchers such as Schroder *et al* (2003) and Smith *et al* (2003). These diversities formed the basic basis of selecting research participants and they included but not limited to; age, gender, level of formal education, marital status and individual life project. Unlike in quantitative research where a researcher can predetermine the sample size, in this study the sample size of 50 was determined in the course of the study through the process of saturation.

In selecting research participants for this study, I relied heavily on snowball sampling techniques because of the sensitive nature of the topic and legal framework governing self disclosure of HIV seropositive status in Kenya as articulated by HIV and AIDS prevention and control Act 14 of 2006. Before using this technique to select my research participants, I had to do a number of preliminary preparations for about two months which was meant to ease my access to my research participants. First, I rented and moved to a house in Mosocho market which was one of the most popular markets in the division. The market was strategic because it was in close proximity to Raganga Health centre which was offering comprehensive HIV treatment and it hosted the offices of most community based organizations and Non Government organizations such as the German funded Fulda which was fighting Female Genital mutilation (FGM) through alternative rites of passage. The market was inhabited by both the indigenous people "*Abagetutu*" and immigrants from other places of Gusii who have either bought land and settled there or rented houses.

The strategic nature of this market worked to my advantage as I negotiated access to would be research participants. First, being close to Raganga Health Centre which was offering comprehensive HIV/AIDS treatment, I would visit the facility in many occasions spending time with both the service providers and their clients. As I interacted with them, I explained to them what my mission was in the area. With time, people came to know what my research was all about and whom I was targeting. Second, being a host of several community based organizations, I would accompany officials of these organizations especially those dealing with HIV/AIDS as they carried out their everyday

community activities. This accorded me the opportunity to explain to the community members what my research objectives were. As I interacted with the community I also started creating social networks. Third, being inhabited by people from various places eased my acceptance into the community. This enabled me to participate in their social activities including attending funerals.

During my stay, a few community members started sharing with me albeit in confidence about their everyday struggles with HIV/AIDS. This however started with general communication of social problems affecting them, but with time, they developed trust in me and disclosed their HIV seropositive status. Those who on their own volition shared with me their HIV seropositive status and were above 18 years were then requested if they could participate in the study. This request was done after I explained to them the objectives of my study; the kind of questions that they would be asked and their right to decline to participate in the study, to withdraw at any stage, or to decline to answer whichever questions they did not feel comfortable sharing with me. The study participants were also assured that they would remain anonymous and that their identities would not be revealed in any way. Those who gave verbal consent were then included as participants in this study. I relied on verbal consent only because as Miller and Bell (2002: 54) argued, "written consent has implications for those trying to access hidden groups or those who are difficult to access and where people may not want anything bearing their signature as evidence that they participated in such an interview."

Those who consented and participated in the study were then requested to link me to other people whom they knew to be HIV positive. At the initial stages though, I asked my link person not to divulge the identity or any details of the 'would be' research participants to me. This strategy of linking with 'would be' participants was made possible because a number of HIV positive patients had informal psychosocial support groups for emotional and social support to each other as they struggled with their illness. These psychosocial groups consisted of a social network of individuals who knew each other through attending patient support centre (PSC) services, when seeking HIV treatment. Such groups were mostly known to members only.

After my link person made contact with the 'would be' participant, he/she would explain to the person about me and my research objectives. The link person would assure the identified person that his/her identity had not been made known to me. If the person consented to participate in my study, they would then agree on how best to contact me. In most cases the link person would meet me with the person and introduce him/her as a friend. Such encounters were most often camouflaged as coincidental. After introduction we would spend some time together talking on everyday general issues as we sought to know each other better.

In my first encounter with the participant, I avoided talking so much about my research though I made it clear what my mission in the area was. To create rapport, we talked about various social problems affecting the community without directly talking about HIV/AIDS. In the subsequent encounter, I would start being open about my study, explaining the details of what exactly my objectives were. I would also share my life stories with the participant. Sharing such personal stories helped create trust and confidence. Though the person was introduced to me by the link person, I never assumed that such a person was living with HIV .This is why I worked hard to create a trusting relationship with the person so that he/she could be free and have confidence in me before sharing his/her private life with me.

As found out in this study, creating trust and confidence among various research participants especially when dealing with a very sensitive research is not a onetime process. It is a process which requires a lot of patience and a researcher has to highly uphold ethical standards, especially confidentiality. As observed, most participants would do their own assessment and evaluation to determine if I could be trusted with confidential and private personal information. They could want to know what the link person had shared with me regarding their personal life, and others would inquire from other community members what I shared about other people's life in the community. This experience underscored to me that when dealing with sensitive topics, research participants have their own interests which must be met to their satisfaction before they

agree to participate. I also realized that meeting research participants' interests is a process which takes a long time and requires patience on the part of the researcher.

Averagely it took a minimum of between one-two weeks for most people to start opening up on their private personal life. Even as they did so, most of them never consented directly to participate. Instead they would "volunteer" to help me with information about my study as they had heard or experienced from another person who was HIV positive. With this "indirect" consent to participate, I would still take time to explain to the participant what my research was about, his/her right not to answer any question asked, the right to withdraw from participation and assurance that all the information shared would be held confidential. After explaining all this, I would again request if he/she was willing to participate in the study.

The reason why I had to renegotiate consent even after the participant had agreed was informed by three factors. First, the initial interaction with the participant was taken as a process of creating confidence and trust given that my study was very sensitive. This was not taken as a guarantee that the person would participate. Given the fact that this took a lot of time, most of which involved continuous interaction with the 'would be' participant, there was need to renegotiate consent to ensure the participant agreed without feeling obligated to do so because of our long time interaction.

Second, since I was depending on referrals from those I had interviewed to get new participants, I realized that some of my link persons would distort information on what my research was about in order to influence one to participate. For example, one of my link persons informed another that I was doctor who was recruiting those who were HIV positive for financial assistance and access to new HIV treatment. Whereas I had told my link person that I was a doctoral student in France, I never told him that I was a medical doctor or that I was involved in the recruitment of people living with HIV for treatment and financial assistance. My link person misrepresented my mission in the field so as to get a participant for me. He did so by taking advantage of what the 'would be' participant

was experiencing because he had developed resistance to antiretroviral therapy and had financial difficulties.

Third, given the fact that most of my research participants were drawn from informal psychosocial groups of people living with HIV, some of those who were approached felt that they should not turn down my link person request to participate in the study. This meant that some of them would agree to participate as a show of support to my link person and not by their own volition.

The use of snowball sampling technique had it is own difficulties. Whereas this technique validated my presence and vouched my trustworthiness among the people living with HIV/AIDS, it made me to be identified not as a researcher but a person dealing with "HIV/AIDS" people. This made some people to avoid interacting with me for a long time for fear of being construed to be HIV positive. This was not a unique case to my study. Other researchers such as Shihidian (2001) who did research among the Iranian exiled community was identified with political affiliation of her references. To minimize this I used the community gatekeepers and opinion leaders to change this perception by creating awareness of what my study entailed and its importance to the community as everyone was being affected by the disease. In using this method, I managed to have 37 research participants in a span of 12 months.

Apart from snow ball sampling, I also relied on purposive sampling to select my research participants. In this method, I directly approached those community members who had publicly disclosed their HIV seropositive status. As noted, most of them were living positively with HIV/AIDS and were involved in the fight against HIV/AIDS stigma in the community and were commonly referred as *watu wa ukimwi* "people of AIDS". Since they had publicly disclosed their HIV seropositive status, I would approach them directly and explain to them about my study. Most of them agreed to participate immediately but I would request for an appointment at a later date for the interview. I did this to give them time to ponder about my request; given consent to participate in a research is not a one-time process. It needs consideration of many factors by the researched. This was also

meant not to create an impression that I was taking advantage of them because of their public disclosure.

Participants who gave their consent to participate were first made aware of the purpose of the research, their rights and assurance that all the information they would share would be held confidential. Though most of them had no problem with participating in the research, some had expectations of being compensated in kind for their time and information. This expectation was not strange because almost all community based organization (CBOS) and Non government organizations (NGOs) in the study site compensates them for participating in HIV/AIDS campaigns. I was also expected to compensate them given that my research was on HIV/AIDS.

This expectation by my research participants to be compensated in an academic research created an ethical dilemma for me. As a Kenyan scholar, it is unethical to compensate research participants for a purely academic study. However, here was a situation where non-academic actors dealing with HIV/AIDS have been compensating their participants in kind. This was worsened by the social construction of HIV/AIDS public disclosure by HIV seropositive patients as a "professional qualification" to engage in HIV/AIDS related activities as an expert who must be paid "professional fee" for the time and knowledge (expertise) given.

This ethical dilemma in relation to compensation of research participants is not peculiar. According to the World Council of Churches study document on AIDS (1997), ethical theories are based on differing views, values and principles. It is therefore the duty of the researcher to adhere to his/her institutional ascribed ethical theories. From this, I made a decision not to compensate my research participants. Instead I took time to explain to them the utility of my study not only to their individual life but to the whole community. Those who accepted to participate without compensation were included as part of my sample. A total of 9 research participants were selected using this method.

My long stay in the field and participation in community activities as I went on with field work made me to be known as an "AIDS researcher" to most people. This made some community members to start approaching me albeit secretly for "expertise" advise on their struggles of living with HIV. Most of those who approached me in this way were afraid of being discriminated and stigmatized because of their HIV seropositive status. Although I had some understanding of HIV/AIDS through anthropological readings and the general knowledge I have acquired, I was nevertheless not qualified as an expert on biomedical aspects of HIV/AIDS which those who approached me were interested in.

However, using my anthropological knowledge about HIV/AIDS, I delved to understand their HIV/AIDS problems from the social rather than biomedical perspective. In particular, I was more concerned with understanding how structural and contextual factors have shaped their responses to HIV/AIDS diagnosis. I did this from my anthropological understanding that if these factors are understood and dealt with; they will be empowered to deal positively with their HIV/AIDS diagnosis. Using this approach, I managed to empower three community members to live positively with their HIV/AIDS diagnosis. These three later formed part of my sample size. In total I had a sample size of 50 research participants in a span of 15 months.

**Methods of data collection**

The focus of this study was on the socio-cultural meaning of death from HIV/AIDS and how it influences HIV/AIDS prevention. In essence this study sought to understand how people perceive death from HIV/AIDS, their experiences of dying from HIV/AIDS and how they make sense of their lived experiences with dying from HIV/AIDS and how this influences their prevention action in their cultural context. These issues therefore call for in-depth understanding in a particular cultural context and not generalization. Consequently, this study relied on qualitative research methods for data collection because they allow the researcher to go into the depth of the participant's experiences, social processes and discourses (Mason, 2002).

*In depth conversational interviews*

This study was carried out from the ontological position which suggest that people's knowledge and experiences are best understood and interpreted through an interactional process involving the researcher and the researched in a particular context. Subsequently, in this study I used in- depth conversational interviews in the generation of knowledge. In this context I interacted with my research participants in a two way process whereby I not only asked them questions about their lived experiences but also allowed them to ask me questions as a way of sharing my life experiences (Merrill, 1999). By doing so, I had an equal power relationship with my research participants in the generation of knowledge because I would ask and respond to their questions in an effort for them to clearly understand the phenomena under study.

In-depth conversational interviews were guided by broad guiding themes (**see Appendix 4.1**). These themes helped me to create conducive environment for my research participants to talk about their lived experiences in relation to HIV/AIDS and at same time keep them in track on the main issues of the study.

Data from in-depth conversational interviews were recorded either by tape recording or note taking. The decision on the method of data recording was solely determined by the research participant's consent. This meant that before recording the interview, I discussed with the research participant if he/she was comfortable to be tape recorded. Those who gave consent to be tape recorded were given assurance that their information would be confidential. Forty six (46) of the research participants agreed to be recorded. The remaining four (4) research participants refused to be tape recorded for fear of their "voices" being identified by another person who knew them in case I lost the tape recording device by accident. Those who refused to be tape recorded were mostly those research participants who had approached me albeit secretly for help over their struggles with HIV/AIDS. Their interviews were recorded by taking notes. Though tape recording formed a major component of collecting data, I also took notes in my fieldwork notebook on the major issues which emerged.

*Key informants interviews*

Based on their social roles and knowledge about the community culture and HIV/AIDS, nine key informants were purposively selected. These key informants were deemed to have specialized information about HIV/AIDS because of their position and roles in the community. Their interviews were guided by guiding questions (**see Appendix 4.2)** and were tape recorded. The key informants were:

1. Two religious leaders, one from the Catholic Church and another from the Seventh Day Adventist (SDA) church. These were the dominant religious denominations in the area. The two were selected because they were not only involved in inculcating moral doctrines to their followers but were also involved in presiding over funerals in the community.
2. Head of the patient support centre (PSC) at Kisii teaching and referral hospital (KTRH). This centre deals with HIV/AIDS prevention and treatment. It is a referral centre for HIV/AIDS treatment from all health facilities in Gusiiland. The head of this centre has been in office for over ten years.
3. Two members of Gusii council of elders who were residents in the site of study. Council of elders is a group of old and respected people in the community who had come together by virtue of their long experiences to act as custodians of the community heritage and welfare. This group was formally registered in the ministry of gender, sports, culture and social services.
4. Four lay community members who had continuously resided in the study site since the advent of HIV/AIDS among the Abagusii. These members comprised of two men and two women.

*Participant observation*

During my field work, I interacted with the community members by joining them in everyday life activities. Joining community members in their social activities was almost mandatory given the fact that I was a member of the larger Gusii community. Therefore as an insider researcher, the community first expected me to meet my social responsibilities which entailed attending and participating in their everyday life activities as a community member than a researcher. This was not peculiar to me as other

anthropological researchers such as Masese (2011) and Nyamongo (1998) who had researched in the community as insiders had in several occasions adjusted their field work schedule in order to meet the community expectations such as attending community members' funeral services or visiting the sick. This shows that the community judges the insider (emic) researcher against different standards of social norms compared to an outsider (etic) researcher.

As I joined community members in their everyday life activities, I directly observed and participated in them. Some of the activities I participated in were funeral organization community members. Although among the Abagusii funeral arrangements are for immediate family members, other community members have a mandatory responsibility to participate. Therefore, to avoid being judged harshly by community members, I had to participate in some funeral arrangements.

When participating in these activities, I would in most cases engage in informal discussions with community members. These informal discussions helped me to understand some issues which were not clear during the conversational interviews by contextualizing them. This was important because I carried out my study from an ontological perspective that saw interactions, actions and behaviour as central in understanding lived experiences of death from HIV/AIDS. Data from participant observation and informal discussions were recorded as daily field notes in the fieldwork note book. This data was used to augment data from in-depth conversations and key informant interviews.

*Data analysis*

The narratives from in-depth conversational interviews formed a large corpus of data analysis. These narratives were taken as discourses that not only transferred information on how people perceive death from HIV/AIDS, but also their experiences of dying from HIV/AIDS and how they make sense of their lived experiences while dying from HIV/AIDS and how this influences their prevention action in their cultural context.

Audio taped narratives from in-depth conversational and key informant interviews were first transcribed *ad verbatim* to ensure that all the emerging issues were captured during analysis. Individual transcripts were then read and re-read several times to identify key themes, which were then noted. Similar themes, together with their supporting verbal quotes, from all interviews were grouped together to facilitate easier analysis.

In order to understand the socio-cultural meaning of death from HIV/AIDS and how it influences HIV/AIDS prevention, narratives obtained from interviews were analyzed using hermeneutics methodological framework. In this case, individual parts were examined in relation to the whole and relating one research participant's lived experiences from HIV/AIDS with those of other research participants. In addition, these lived experiences were examined in relation to HIV/AIDS prevention strategies namely: abstinence, being faithful and condom use (ABC). Further, the analysis utilized Ricouer's (1980) notion of "symbolic senses" to examine symbolic use of language and the common metaphors that research participants used in reference to their lived experiences with HIV/AIDS and prevention action. In doing all these, themes that emerged consistently in most interviews were noted. Unique themes were also noted. All these themes were then discussed with some community members who had participated in the study to determine if they were a true reflection of what they said. After this, these themes were used to discuss the socio-cultural meanings of death from HIV/AIDS and how they influence HIV prevention.

**Maintaining critical distance as an insider researcher: Personal experience**

Death is a very sensitive topic to explore as a researcher. It is a topic which is governed by taboos, rules, regulations and norms in most Sub-Saharan communities. This makes it a rare topic of interrogation in public discourses. However, it is among the very few universal features which every person must experience. This makes everyone an "insider" when it comes to studying death as captured by Professor Douglas Davies in Woodthorpe (2011), "we are all participants in mortality, not just as observers".

This universal reality about death means that when one is studying it, in one way or the other, one is studying about personal experiences about death. This raises a number of questions: how does one detach from the research narrative while knowing very well that the subject under investigation will be the one they will encounter eventually. This makes studies on death to be highly personal and reflexive due to personal emotions (Valentine, 2007; Woodthorpe, 2011).

Death is a very emotional and most often tabooed subject. Then how can a researcher detach him/herself from the emotions associated with it in the field. Yet, in most Sub-Saharan communities, death emotions are collective experiences meant to demonstrate solidarity with the bereaved family! As observed by Hochschild (1979), people are not only socialized to act their emotions in particular ways, in certain situations but also to feel some certain emotions during specific situations.

As an anthropologist studying the socio-cultural meanings of death from HIV/AIDS and how they influence HIV/AIDS prevention, these issues confronted me as I tried to maintain a scholarly detachment in data generation and analysis. This detachment was not influenced by the quantitative researcher's notion of neutrality as a means of maintaining intellectual objectification of the topic and participants. Rather I wanted to reflect on whether or not it was possible to maintain a critical distance when researching on death, which is among the very few universal features affecting everyone but laden by subjectivity due to personal experiences and cultural background. In doing so I wanted to make transparent my experiences and how I (re)negotiated the challenges of scholarly detachment.

The quest to maintain a critical distance was prompted by my personal experience about death, the nature of my study and the principle methods of data generation and analysis. In relation to my personal experience about death, first and foremost I was carrying this study as an insider who has been culturally socialized about various aspects of life and death in the community which include but not limited to taboos, rules and norms governing life and death, various constructions of death and the rituals involved in death.

Second, at a personal level I have encountered death through the death of close kin members and friends and lastly, the reality that I will encounter death at one point.

The principle methods of generating data for this study were: participant observation and in-depth conversational interviews. These methods entailed immersing into the life worlds of those experiencing or facing death from HIV/AIDS. This immersion had an impact on my emotions as well as those I was researching. This study was also an inductive form of study which was shaped by the social constructivist ontology and interpretative epistemological approach. All these issues require the researcher to be transparent on how his/her personal experience and cultural background helped in shaping the research process. This is important as it enhances the credibility and trustworthiness of the research (Hocky, 1990; Kristvik, 2012; Letherly, 2000).

As an emic researcher, my understanding about death from HIV/AIDS was first influenced by my cultural socialization of it as a "bad death" since its advent in Kenya. This construction informed my attitude towards such deaths and those infected by HIV/AIDS. At an individual level, I have also witnessed death from HIV/AIDS among my friends. These experiences had a profound impact on my perception and understanding about death from HIV/AIDS. Initially I wanted to detach my experiences so that I can be a "neutral" investigator whose sole role was to produce "unbiased" findings. However, in the course of fieldwork, I realized that it is through the lens of these experiences that my interpretation and understanding of death from HIV/AIDS would come. For example, through these experiences, I learnt how community members use language[23] to infer to various causes of death. Such experience thus formed the basis of understanding and interpreting behaviour in relation to a particular death.

The importance of personal experiences in understanding behaviour in research has also been observed by Rosaldo (1993). According to Rosaldo, it is through the experience of

[23] When the cause of death was stigmatizing, metaphors such as "he/she died because of eating badly" was used. This metaphor meant the person died as a result of sexual immorality and by implication HIV/AIDS. Direct reference to the cause of death was done when such cause was not stigmatizing such he/she died in a road accident, died from cancer or old age.

the death of his wife that he fully understood the rage that Ilongot men undergo after bereavement:

> *Only after being repositioned through a devastating loss of my own could I better grasp what Ilongot elders mean precisely when they describe the anger in bereavement as the source of their desire to cut off human heads.* (Rosaldo, 1993: 168)

Admittedly, my personal experiences may have blurred the boundaries between personal and my research participants' understanding of death from HIV/AIDS. It is important, however, to underscore the fact that the lives of participants "are filtered through us and the filtered stories of our lives at present (whether we admit or not) in our written accounts" (Cotterill *et al* 1993:74). Consequently, in making sense of my personal experience in relation to that of my research participants', I was guided by Visser (2017) observation that in research on death, the researcher and the researched share their subjectivity within a given research context. In this regard *inter-subjectivity* (Lakoff and Johnson 1980) formed the basis of understanding and interpreting data.

My personal experiences also had a profound power of shaping my research. Though from the onset I hadn't anticipated the death of any of my research participant, the death of 35 year old Mr. Nyabuto drastically changed how I carried on my fieldwork afterwards. Nyabuto was my second research participant to be interviewed. After the interview we developed a personal relationship. He could sometimes call me to inquire about my progress in the field and in some instances; I used to find time to visit him and his family. In most of our interactions, Nyabuto would confide in me his personal struggles with HIV/AIDS and I would encourage him not to lose hope. Five months after interview, he died. This experience emotionally affected me. It made me realize how fragile life is especially to my research participants. I had to abandon my fieldwork for a while so as to participate in his funeral arrangements.

After the burial, I found myself relating much of my experience with him in subsequent interviews. This made me to question how close I should be with my research

participants. How much should I allow the research participant to disclose to me? How much should I disclose to my research participants? These three questions have implications on the critical distance and the level of rapport the researcher must maintain in the field. After this experience, it dawned on me that the level of rapport and critical distance to maintain with research participants should be guided strictly by the research questions under study. This meant that issues which were not directly related to the research questions were just acknowledged but efforts were made not to turn them into therapeutic encounters.

The use of participant observation and in-depth conversational interviews as my methods of data collection also created a challenge of how to maintain scholarly detachment. These methods require the researcher to be immersed in the research participant's life world in order to understand and interpret their experiences. In using participant observation for instance, I found myself in a dilemma in a number of occasions on whether to use covert or overt methods of observation. This dilemma was compounded by the fact that in the Abagusii funeral ceremonies, the immediate kinship members are always keen to know the social relationships of mourners to the deceased. This means all mourners are required to introduce themselves to close kinship members of the deceased and to other mourners. In addition, although funerals are public ceremonies it is only close kinship members who are required to take active roles.

These two features about the Abagusii funerals meant that if I used covert methods of observation, it would not only be unethical but also create suspicion among mourners if discovered. Similarly the use of overt methods required introducing myself and at same time providing details about my research. This was also problematic as an insider researcher who is culturally socialized to act my feelings in an empathizing manner as a way of demonstrating solidarity with the deceased family but not as a context of researching. These dilemmas posed a challenge to me on what indeed constitutes a critical distance in the field and its implications on a study, which requires immersion in the research participant's life world. In this context I used my own discretion to decide

which method of participant observation to use in a particular context. This decision was solely based on the utility of each method to produce rich data in a specific context.

These challenges I faced while trying to maintain critical distance is because death is not only a sensitive topic to explore but also a universal feature where everyone is an insider. Consequently, it is not possible to maintain a critical distance or scholarly detachment when researching on death and people associated with it. It is therefore important for the researcher to be transparent on how his/her personal experiences with death shaped the study. By doing so the credibility of the study is maintained.

## CHAPTER FIVE

## DEATH FROM HIV/AIDS AND ITS MORAL RECONSTRUCTION

*……Death is a cessation of life….*

*……in itself it is not "something" but a lack of "life"…..*

*….thus death is not ontological but a construct of….*

*…it is the fear that we don't know…….*

*….but faith helps one deal with the unknown…..* (Anonymous Author)

### Introduction

In this chapter I discuss the socio-cultural meaning of death from HIV/AIDS. In doing so, I argue that this death is constructed as "bad death'' because it is a social threat to the regeneration of the community through social reproduction and negatively affects the corporate social identity and solidarity of group members. As consequence, those affected cope with it through moral reconstructions which mostly aim at concealing it.

### Social construction of death among Abagusii

In most African communities including the Abagusii, death is seen as a transitory stage into the spiritual world of ancestors. In this case when a person dies, his whole being except the physical body moves into the spirit world where it receives another body identical to the body left in the physical world. In the spirit world, it becomes a living-dead where it has more influence on the living. For this transition to occur, death rituals involving the body are performed. This makes death to be experienced collectively unlike in the Western world where it's an individual and interpersonal event which is marked by a single event ceremony to signify permanent exit (Taylor et al 1987; Giddens, 1989).

Though death is constructed as a transitory stage, it is a tabooed subject and people use euphemism to refer to it (Nyakoe *et al* 2012). Thus in everyday life death is conceptualized by metaphors of journey and rest. These metaphors denote that human beings are travelers on earth where rest will be attained when the final destination is reached. As a journey, human beings have to pass through several stages of life to reach the final destination which is perceived as superior. These stages are the rites of passage where an individual is obligated to meet the ascribed cultural expected standards of each

rite (**see chapter three**). This means that the final destiny- death must only occur at old age when all the ascribed cultural expected standards of each rite of passage are deemed to have been met. Death before this is accomplished is constructed as "bad death".

Despite death being construed as a transitory stage, it is not still an accepted event in everyday life. Thus it is believed to be caused by external forces such as witchcraft or individual factors such as non-observance of particular taboos. This means that even if death is caused by known natural causes, its causation is primarily attributed to social factors such as witchcraft. This makes natural causation secondary. This is contrary to the Western world where death causation is construed as natural.

As a transitory stage, death generally comprises three elements which influence social behaviour. These are: self esteem and preservation for the individual, social lineage reproduction for the family and preservation of esteem for the society. All these three elements are inextricably intertwined in that they depend on each other. That is, the survival of the society depends on the family and individual. This makes death of the individual, not to be seen as a loss of an individual but as a society losing part of itself. Therefore in order to preserve itself, the society uses "social grafting" and social reproduction processes.

Social grafting is a process whereby the society perpetuates itself without recourse to social reproduction. It constitutes immortalization of the dead through the naming of the living after the departed. Through this process, the individual is not only born, but society is able to preserve its cultural identity, traditions and character. However, social grafting is mostly influenced by the constructed type of death (**see chapter three**).

Social reproduction is a process by which people in a particular community perpetuate themselves and their identities from generation to generation. This is achieved through giving birth to young ones as per the *cultural expectations*. Cultural expectations here denote: bearing young ones in a formalized marriage union and specifically, a gender preferred child, in this case a son. Therefore those who are unable to engage in social

reproduction are stigmatized. Consequently, any death that threatens the preservation of the individual, family and society through social reproduction or grafting is construed as a "bad death".

Death in the community is also constructed through Christian religious schema as a transitory event to a better destination. In this construction, death of the body is not the final death of a person, as the dead body shall resurrect and either go to eternal life for those who lived a moral life or perish in hell "permanent death" for those who lived an immoral life on earth. This is evidenced by the type of death one experiences.

In the Christian religious schema, the successful transition to afterlife entirely depends on an individual way of life on earth, whereby a person has to give his/her life to Jesus Christ and adhere to the commandments as stipulated in the bible. This is unlike in the traditional Abagusii schema where such successful transition is both an individual and collective function. It is individual in the sense that, one has to live in the culturally defined moral life and meet all culturally expected life standards. Once all these individualized expectations are met, collectively the society will then aid the individual to transit to afterlife through performance of death rituals.

Among the Abagusii, Christianity was introduced in 1890s by white missionaries. Their core mission was to convert Africans from "paganism" to the Christian way of life. This conversion entailed Africans abandoning their traditional way of life and embracing the European way of life which was seen as "modernity". This religious changes transformed people's way of life in terms of their world view and notions of personhood, life, death and afterlife. Despite this transformation, the Abagusii way of life is governed by both traditional and Christian religious beliefs.

**Social construction of death from HIV/AIDS**

The way people make sense of death from HIV/AIDS was found to be influenced by traditional and Christian religious beliefs about life, death and afterlife. These beliefs were based on the ascribed expectations of an individually lived life as outlined by

Christian religious doctrines and the cultural value system of the community. In addition these meanings were further fortified by global forces which influenced initial responses to HIV/AIDS in most countries especially in Sub-Saharan Africa as hereafter discussed.

*Death from HIV/AIDS as bad death*

Death from HIV/AIDS was socially constructed as bad death. This construction arose from cultural discourses governing life, death and afterlife as explained by 70 year old Mr. Nyariangi:

> *Culturally when a person dies, there are some rituals which must be performed. These rituals are very important for the person to transit to become an ancestor. However, with HIV/AIDS it was not possible to carry out these rituals…… I can recall during the initial periods of this disease, those who died from it were wrapped in black polythene papers. Nobody was allowed to view them and they were interred immediately they were brought from the mortuary. I don't know why this was the case but the local government administrators used to tell us it was government policy. This created fear among many people. As a consequence, most people avoided attending funeral ceremonies where the person was perceived to have died of HIV/AIDS for fear of contamination. Actually such ceremonies were very brief and only conducted by very close kinship members. It was as if the deceased was an outcast!*

Mr. Nyariangi's description of death from HIV/AIDS as a bad death is based on two factors which are somehow interrelated: One, that at the advent of HIV/AIDS in Kenya, it was a government and public health policy that those who died from HIV/AIDS were interred immediately and their remains not displayed for public viewing as a way of "preventing it's spread" (Ogot, 2004). This curtailed the performance of death rituals because of non-involvement of the corpse. These rituals are important not only in affirming the social status of the deceased but also in transiting the death's spirits to the ancestral world. Two, fear of contagion and contamination meant that most people would

not attend the funeral ceremony of the deceased. This in essence denied the family and lineage the context to give respect and affirm status of the deceased. As observed by Masese (2011) the status of the deceased and lineage is affirmed by how well the funeral rites are organized and the number of people who participate in it. Therefore when few people participate in the funeral ceremony, it is a social indication that such death is bad.

Though Mr. Nyariangi's observation can be traced to the period of moral panic which characterized the initial response to HIV/AIDS pandemic (Ogot, 2004), the fear of contagion and contamination is still rampant among many people. This is despite the fact that most people are knowledgeable about the HIV virus and how to avoid contracting it. As a consequence, some rituals such as washing and dressing of the corpse by close kinship members have been taken over by "professionals" at a fee. These basic rituals were meant to symbolize and affirm social bond of the deceased with kinship members. However "professionalizing" these rituals due to HIV/AIDS has created social boundaries and distance between the deceased and kinship members making such death bad as explained by 33 year old Mr. Mogaka:

> *When my cousin passed on after a long illness, I observed that nobody wanted to touch his body. It was frustrating to see his body on the mortuary slab unattended for a very long time. Everybody was disinterested with it…yet in the funeral arrangement meetings we were referring to him as "our late beloved brother". I had to do something. I borrowed gloves from the mortuary attendant and started dressing it. Suddenly, my kin yelled at me to stop touching the body as I would "contaminate myself with AIDS". Initially I took it as a joke until two brothers of the deceased came and pushed me off as they shouted, "we don't want more deaths from this dirty disease in our family. Let the professionals who we have paid do their work. We have nothing to do with that body but just to inter it because it is a must.*

Mr. Mogaka's experience can best be understood by drawing inference on how the Abagusii dealt with bad death. In the community bodies whose death was construed as bad were perceived as pollutants and people were not allowed to get in contact with them for fear of contamination. Therefore wherever such deaths occurred, the bodies were disposed off with no regard to cultural requirements governing interring. Such disposal was seen as equivalent to "*throwing away waste*" as captured in the following interview.

**Researcher:** You said people who died from HIV/AIDS were not buried but thrown away. What do you mean exactly?

**Nyariangi:** Yes. They were just thrown away because no one wanted to touch such bodies and prepare them for a decent burial as per the Abagusii traditions. Death from HIV/AIDS was worse than suicide. The victims of suicide were not buried in the graves but just covered with soil on the spot where their bodies were found. Nobody touched such bodies because of the belief that their evil spirits would possess those who get in contact and cause them to commit suicide also. So if you are not buried in a grave, it's like you are thrown away as waste?

**Researcher:** Are you implying that those who died from HIV/AIDS were not buried in graves?

**Nyariangi:** They were buried in graves, but who cared on how they were laid in the grave? Who dared to view or come in close contact with them? Actually they were just thrown into the grave! Just buried like a dog! No ceremony followed after this. Nobody wanted to be contaminated with their disease!

**Researcher:** This seems to be the case when HIV/AIDS first came to this community. Is it the case now?

**Nyariangi:** Nothing has changed except modernizing how this death is handled.

**Researcher:** What do you mean?

**Nyariangi**: I mean people wearing protective gear in their hands whenever they touch such bodies…you will always see people very careful whenever they come

> in close proximity with such bodies. I think it just one way of modernizing bad death but it still remains bad!

Sufficing from these narratives, it is clear that death from HIV/AIDS is seen as bad because it threatens the community's way of life in terms of group solidarity and identity. These threats emanate from three interrelated sources: death from HIV/AIDS creates social distance (boundaries) between the deceased and kin members thus affecting their social functionality with each other; it negatively affects the social identity of kinship members through associated stigma of having one of their own dying from a stigmatizing illness and lastly it devalues the corporate social status of group members due to their failure to accord their deceased kin decent funeral rites as per the cultural expectations of the society due to fear of HIV/AIDS contagion and contamination.

As a threat to group solidarity and identity, the social organization of funerals of those who die from HIV/AIDS has thus evolved from being communal to family affairs. Among the Abagusii, for example, funerals are sites where community members demonstrate and exercise their reciprocity and mutual social responsibility to the deceased and bereaved family. This is unlike in the western world where funeral parlors have taken the private role in disposing dead bodies due to increased medicalization of death in those countries (Illich, 1976; Aries, 1981; Armstrong 1987).

This change in the social organization of funerals was observed to affect the decent burial of those who died from HIV/AIDS in two ways. First, the families affected found it difficult to attract social, emotional and financial support to organize the funerals. Two, death from HIV/AIDS attracted minimum funeral attendance. These two factors militated against a decent burial befitting the social status of the dead persons. Traditionally, a decent burial is reflected by how well a funeral ceremony is organized and the number of people attending it. For example, huge numbers symbolized respect and communal acceptance of the deceased.

Mr. Maranga, a 32 year old man also saw death from HIV/AIDS as bad because it is equivalent of "*killing oneself*". According to him, "*killing oneself*" means that the victim is solely to blame for his/her own death because of not taking known precautions of avoiding risk of infection. Such failure is equivalent to committing suicide which in reality attracts no public sympathy to the victim as he explains:

> *In the world today every person knows how to avoid contracting HIV/AIDS in everyday life…..the information is everywhere that sexual immorality is the sole cause of AIDS. Those who are immoral are even told how to avoid infection using simple and easy strategies……..with all this information it is very careless for anyone to die of AIDS……. I don't understand how someone can be told that this food is poisonous and still go ahead and eat it. Is this not like committing suicide? This is why those who are dying from HIV/AIDS suffer alone with no sympathy at all. Even in their death people attend their funeral just as a formality.*

As noted from Mr. Maranga's explanation, HIV/AIDS is individualized as a disease of lifestyle and choice. Thus dying from HIV/AIDS is perceived as the responsibility/choice of the individual devoid of contextual factors which cause vulnerability. This makes those who die from HIV/AIDS to be blamed for their death causing them to lose their social status and identity in life.

Mr. Maranga's explanation was further supported by Mrs. Nyangweso, a 65 year old widow who said:

> *The problem with HIV/AIDS is that even if you were very much respected in the community, no one would respect you in death. All the good deeds you did are permanently erased. Actually what people might remember is how your sexual immorality killed you. This remembrance, however, is meant to show how useless you were to die of AIDS of all the diseases! Despite your social status in life, you will be buried like a dog.*

Although the attribution of blame of dying from HIV/AIDS was individualized, its severity in the construction of death from HIV/AIDS as "bad death" was relative to gender. As observed in this study, women who died from HIV/AIDS were severely ostracized, regardless of their socio-demographic variables such age, marital status and level of formal education and structural factors which made them vulnerable to infection. However, among men this was tampered with by blaming such death to either women's (co)omission or other powerful contextual forces beyond their control. For example during field work, it was observed that whenever a married man died of HIV/AIDS, his wife was blamed for it. This blame was mostly based on "alleged failure" by the wife to "treat" her husband well, and thus making him vulnerable to sexual risky behaviour. In this attribution of blame, the role of the man in causing his own vulnerability was muted.

The attribution of death from HIV/AIDS to women can be attributed to the cultural position of women in the community. According to Masese (2011), women are perceived as outsiders both in their natal and bridal homes. In their natal home, a woman is seen as an outsider because she is supposed to get married in order to acquire proper identity. In the bridal home, despite acquiring proper identity, she is still considered as an outsider. This ambivalent position of women makes them an easy target of victimization because they lack security and social support both at their natal and bridal homes. Therefore victimization of women can be construed as a tactic of protecting men's social status and identity which is being threatened by death from HIV/AIDS because of their powerlessness.

Death from HIV/AIDS was also construed as bad death because it curtailed the regeneration of the community through social reproduction. As a consequence such a death was seen as a permanent death as observed by Mrs. Nyangweso, the 65 year old widow:

> *My only son was infected by this horrible disease. When we realized this, he had not married though he had a fiancée. I encouraged him to marry and have a child who could perpetuate our lineage. He accepted to marry and was soon blessed with a baby boy. Three*

*months after birth, the child passed on. His mother also passed on two months later. We were all devastated. I encouraged my son to be strong but he too lost the war to this illness six months later. Now I have no one to perpetuate my lineage. This illness has completely wiped out my family and lineage. As you can see I am also on my way out due to old age. I am certain nobody will bury me since i have no son or grandchild to do so!*

Mrs. Nyangweso's observation was also shared by 70 year old Mr. Nyariangi:

*In this community I have seen families being wiped out completely with AIDS. Those who are not married are also not spared. .....this disease has turned marriage into a risky affair. You don't know whether by marrying you are signing your death certificate. I have observed that many young people are not enthusiastic about marriage. This has created a dilemma, which is making the survival of this community brink. .....you don't get married you die without an offspring which is not good. Similarly, you get married and you are at risk of being infected with AIDS. In both cases the young people are dying bad deaths, which are wiping their lineage completely.*

With recent improvement in HIV/AIDS treatment, those who are infected are able to get HIV free children. This has helped the community to regenerate itself. However as found out in this study, those who are born to HIV positive parents, regardless of their HIV negative status are still stigmatized. This associated stigma is used by community members to label such children as "not clean" to engage in the regeneration of the community as elucidated by Mr. Maranga, the 32 year old man:

*The problem of children whose parents were HIV positive is that they find it difficult to get spouses. Despite being HIV negative, most people assume they are still carriers of the disease because their parents had it, and thus they are not marriageable.*

Mr. Maranga's sentiments were also echoed by the head of patient support center (PSC) at Kisii Teaching and Referral Hospital (KTRH) who observed that*:*

> *A number of people believe that children born from HIV positive parents at one point in their lives will revert to HIV seropositive status even if they were born HIV negative. This belief is borne from the lay understanding of HIV asymptomatic period. According to a number of people, HIV takes time before its detected. This period can take a number of years depending on one's body and immune system. Because of this belief, most community members would not like their kin to marry those whose parents were believed to have died from HIV/AIDS. Once your family lineage has been associated with HIV/AIDS, you are also condemned not to have a family. This is the challenge we are facing now despite the great strides in HIV treatment.*

Other research participants construed death from HIV/AIDS as a permanent death because those who die from the illness are not immortalized by their living kinship members through naming of new born members after them. This means that their memory is permanently erased among their kinship members because their death is constructed as a bad death. This was clearly captured in the interview with Mr. Nyachoti, a 37 year old man who is also an HIV/AIDS activist:

**Researcher**: Sir, what made you to be so much involved in HIV/AIDS activism in this area?

**Nyachoti**: After my elder brother died of AIDS, I saw how his immediate family was stigmatized and discriminated. Nobody wanted to be associated with them. So I decided in a small way to fight this stigma and discrimination by standing for their rights and at same time educating the community that those who are infected or affected by AIDS need social support.

**Researcher**: I am sorry for your brother's death and what his family went through after his demise. I really feel for you but I am happy you are doing a wonderful job to help other families not experience the same.....

**Nyachoti:** Thank you for your encouragement. I had to do it because my brother really helped me in my life. He helped in paying my school fees from primary to university. He also secured me a job. He also advised me on marital issues and in other issues of life. He was just good. Unfortunately this disease took him even before my son was born.

**Researcher:** Sorry for that. I can see your pain. Now apart from resorting to AIDS activism, did you do anything in honor of your brother?

**Nyachoti**: I do not get your question clearly.....what do you mean?

**Researcher:** I mean.....you see... I mean like naming your child after him?

**Nyachoti**: mmmm..... eeeh .....yeah .....mmmm... You see, we are Christians, and it was unchristian to name my child after him.....even most people would not have approved it.....!!

**Researcher**: Ok.... does it mean that Christians do not name their children after their kin who have died?

**Nyachoti:** You see my brother died of "that bad disease" and you know it will be very disturbing when the child grows up and he is told that the person whom he is named after died of "that bad disease". .... Very stigmatizing.....! Yeah though I am a Christian.....but you see also if I was to name my child after him there was a high likelihood that at one point in his life, he would be possessed by my deceased brother's bad spirits and cause him to die the same death..... I know you can question me on this but I don't know how it happens that those who are named after the departed mostly take up their traits in life and suffer the same fate later in life. ..... So I hope you understand why I did not name my child after my late brother, though I loved him very much. It is a way of breaking the jinx of bad death... It is very common here.

Data from informal discussions with a number of community members also revealed that people who die of HIV/AIDS are equated to outcasts and therefore their names are not given to the newly born children in the community as per the Gusii custom This stems from traditional beliefs that such people's traits can easily be replicated in those who are named after them. By being denied a chance of being named after, people who die of HIV/AIDS therefore face "permanent death".

In this study, death from HIV/AIDS was also construed as "permanent death" among those community members who confessed Christianity. Like in the traditional schema, the Christians also believe that death of the body is not the end of the person, as the dead body shall resurrect. This means physical death is a "transitory event" to the cosmological world "heaven". For this transition to be successful one must live a moral life at lifetime. However, in the Christian schema HIV/AIDS is morally constructed as a disease for the sinners, immoral and promiscuous people. Based on these moral discourses, those who die of HIV/AIDS not only experience physical mortality but also mortality of the soul which is "permanent death". Peter, a 34 year old catholic priest explains:

> *As a church minister, I find it embarrassing when burying a Christian who has died of AIDS. It is very difficult to deliver a sermon or how to eulogize the person. These difficulties arise from the fact that Christians are supposed to live a moral life in order to inherit God's kingdom.....but when you die of AIDS, it means you lived an immoral life. As a church, we know even if we pray for such a person for God's forgiveness, the person won't go to heaven in the resurrection day.....*

Wairimu, a 42 year old female evangelist with the charismatic church observed:

> *....those who die of HIV/AIDS are immoral people even if they are Christians. Immorality is a gateway to hell. In hell they will be destroyed by fire. So in my ministry I don't waste time going to funerals of those who have died of AIDS. That is a wasted soul!*

*Death from HIV/AIDS as a Shameful death*

Death from HIV/AIDS was socially construed as shameful death because it not only self-devalues the individual but also threatens the social fabric which the society is built on as elucidated by Mr. Maranga, 32 year old:

> *This is the worst disease ever for humankind. Those who have this disease suffer a lot especially when it incapacitates them. Just think of a situation where a grown up man like me has to depend on other people in performing basic biological functions like going to the toilet. This disease renders you as powerless as a toddler! Even your mother has no choice but to help you in carrying out these basic biological functions.... a thing which is culturally not right! This disease really destroys your dignity as a person.*

Mr. Maranga's account reflects the devastating effects of the spoiled identity that HIV/AIDS confers to an individual. As observed by Berger (1990), people invest meaning in their lives which increasingly assumes "objective reality". However, the incapacitation from HIV/AIDS shatters it all through the loss of power of self which leads to overdependence on others regardless of the social values governing social interaction and behaviour among group members in various contexts. This devalues the worthiness of the individual during and after the dying process.

Mrs. Nyangweso, the 65 year old widow who lost her only son to HIV/AIDS also observed that:

> *Death from AIDS is very shameful. It stripped all the respect between me and my son. I had to wash him as a baby. Nobody wanted to come near him. Even when he died his remains were badly handled by my family members... it is something I shall not forget. I wish he had died of a road accident.*

As noted from Mrs. Nyangweso's sentiments, death from a road accident was more preferable than death from HIV/AIDS. This is because in such a death, the victim is not blamed. This is unlike in the case of HIV/AIDS where the individual takes the blame and cannot be absolved from responsibility. This makes those who die of HIV/AIDS to be stigmatized and discriminated.

Ms. Wairimu, a 42 year old female evangelist with charismatic church argued that death from HIV/AIDS is a shameful death because it is a product of sexual immorality. Therefore such a death is viewed as a form of punishment for those who are sexually immoral. This kind of moral evaluation makes community members to rank death from HIV/AIDS lowly. Wairimu avers:

> *AIDS is for the adulterous people, people who have no morals or self control. They must face the wrath of God... their shameful acts must be brought to the open for everyone to see. That is why they must die a shameful death not befitting a human being*

*Death from HIV/AIDS as a social death*

Death from HIV/AIDS was construed as social death because the families which were affected were socially discriminated, rejected and stigmatized. This hindered them from participating fully in community activities. Mr. Matunda, a 65 year old explains:

> *People in this community tend to avoid associating with families which have lost their loved ones through HIV/AIDS. Despite high levels of knowledge about the disease, many people still believe that they can contract HIV/AIDS by associating with close family members of people who have died of AIDS. This has caused members of such families to be isolated. Recently I saw a widow being disinherited by her in laws because to them she was going to die soon. She was even asked not to be using the same watering point as other community members because she was likely to "spread" the disease to others. Actually these are not*

*isolated cases. It is common here for such families to be isolated though in most cases it's done covertly.*

Mr. Nyarongi, notes:

*As a teacher I have observed that children who have lost a parent to AIDS tend to be discriminated by others. In most cases other students refuse to share even text books with them. As teachers we have tried to eliminate this behaviour among our students. However, our efforts are curtailed because such discriminatory behaviour is reinforced by other actors outside the school such as parents. This is why children who have lost a parent to AIDS also die socially. They are viewed as a risk to be avoided.*

Implicit from all these accounts on the social construction of death from HIV/AIDS, it is clear that an individual does not exist autonomously but as a unit in the collective. In this regard, what happens to an individual affects the collective. This makes death from HIV/AIDS a major concern because it does not just threaten the individual social status and identity but the regeneration of the community, social corporate identity and solidarity of group members.

**MORAL RECONSTRUCTION OF DEATH FROM HIV/AIDS**

When death from HIV/AIDS occurs, it creates a major problem to living kinship members. This is because such death not only threatens their social corporate identity and group solidarity but also their existences as a group. As a consequence the living kinship members manage such a death through concealment and silence using various tactics in the social organization of funerals. These tactics aim at camouflaging the threats imposed by the social construction of death from HIV/AIDS as bad, social death and shameful death as hereafter discussed.

*Medicalizing dying and death*

It was common among the Abagusii that any member who was at verge of death was to be surrounded by close kin members at his/her ancestral home as a sign of goodwill and solidarity in his/her dying process. However, this practice was rendered problematic with HIV/AIDS due to two interrelated factors: One, though the society is built on a culture where sympathy and compassion for the dying person is a norm, the fear of contamination with HIV/AIDS threatens such a culture. Two, people who are on the verge of death from HIV/AIDS experience a lot of complications such as diarrhea and severe skin infections due to suppressed immunity. This makes caring for them to be problematic especially for their kin members. As a consequence those who are dying from HIV/AIDS are taken to health facilities for professional care in their dying process.

In this study, medicalization of death due to HIV/AIDS was found to serve two functions: One, it accorded living kinship members an opportunity to show their compassion to their dying kin which was being threatened by the fear of HIV/AIDS contamination. This show of compassion was perceived as important as it warded them from the rant of the deceased's spirits from seeking revenge for being neglected during the dying process. Two, having their kin die in hospital under the care of medical professionals elevated the social status of the living kinship members to other community members for "their efforts in trying to save their kin's life". This social status was very much enhanced if such a death occurred in a private health facility under the care of private medical practitioners commonly known as "consultants". This is because private health facilities and "consultants" are perceived to offer high quality services despite their high cost compared to public health institutions. The head of PSC in KTRH observes:

> *A number of deaths from HIV/AIDS occur in hospitals. This does not mean most people are seeking HIV/AIDS treatment. On the contrary most people do not seek such services due to stigma associated with AIDS infection. Actually this stigma is fortified by the very close kinship members who are ideally supposed to give them social support. However, when those infected are critically sick, that is when their*

*close kin members bring them to hospital and look for the best medical practitioners to treat them. To be honest these belated actions are not meant to save the sick person's life, but it is a public relations exercise for the living members during the funerals.*

Apart from enhancing the living members' social status, dying in a hospital under professional care also helps in "sanitizing" death from HIV/AIDS through the pathologist postmortem report. This report in most cases indicates the immediate cause of death with no reference to HIV/AIDS as the underlying cause. This report is therefore used by the kin members as evidence from medical professionals that their kin never died of HIV/AIDS but from the written health complications in the report. The fact that medical reports are perceived to be more superior due to their scientific rigor in determining the cause of death, it is taken as absolute truth, in comparison to the "word of mouth". Consequently, it was observed that in a number of eulogies, the pathologist postmortem report was the only cited source of the immediate cause of death.

In the period of moral panic which characterized the initial response of HIV/AIDS in Kenya, those who died of the disease were interred immediately. However, as observed in this study, the bodies of those who died from HIV/AIDS were preserved in morgues for a number of days just as those who died from other illnesses. Preservation of these bodies was meant to give the community and close kin members' humble time to organize a "decent" funeral for the deceased. The number of days the body was to be preserved depended on how quickly resources for the funeral are mobilized, how long it will take to mobilize other close kinship members who are living outside the community to attend the funeral ceremony and if there is any pending dead person within the clan awaiting burial[24].

[24] Members of same clan perceived each other as one people due their common origin and destiny. They perceived each other as brothers and sisters. Therefore it was a taboo to bury more than one of their clan members on the same day. This means each clan member must be buried on a particular day, while giving priority to those who died earlier. Also given the fact that most community members profess Christianity and they either worship on Saturday or Sunday, there is an unwritten memorandum of understanding that no funeral ceremony shall take place in these two days. Consequently, most funeral ceremonies are mostly held on Fridays throughout the community.

The morgue where the body was to be preserved also formed a major component in the social organization of funerals by close kinship members. As observed in this study, most people preferred to have their kin's remains preserved in "private" morgues as a symbol of high status to themselves and to the deceased member[25]. This is demonstrated in the public announcement of death and the eulogy, where the exact place of death and preservation of the deceased's remains are given prominence. For example, it is common to see in the public announcement of death sentiments such as,..... *X died while undergoing treatment in **TT private** hospital*. In case *X* died in a public hospital, the announcement will emphasize that, *X died at the **private wing** of YY public hospital*. In some cases these announcement goes further to indicate the medical practitioners who were attending to the deceased. This is also replicated when informing the public on the exact place where the deceased's remains are preserved.....*the remains of X are preserved in **TT private** morgue or they are preserved in YY public hospital, private **wing** morgue.*

*Popular music and death from HIV/AIDS*

It is common that once a person has died, kin members start meeting immediately at the deceased home/house. These meetings are meant to enable community members to console the bereaved family and start organizing for the funeral. During this period, kin members resort to use of popular music to pass specific messages regarding the death of their kin. This is achieved by biased selection of the kind of music to be played throughout the mourning period based on their themes. This is because of the fact that music is enmeshed in the social fabric of the African experience of life to such an extent that it forms a critical medium of individual and communal communication of issues that are critical to immediate existence (Waliaula *et al* 2014).

In Kenya, popular music has been used to advance various discourses of human life. Nyairo *et al* (2005) have shown how popular music has been used for political

[25] Private morgues are associated with superior quality services and their cost is normally high. This association of "private" service with superior quality has also led public institutions to provide services using both private and public sector model. In the private section of the public institution, the services are of superior quality but the cost much higher than in the public section. Accessing and affording private service is therefore a symbol of high social status.

mobilization, identity formation (Waliaula et *a*l, 2014) and in HIV/AIDS intervention (Van Buren, 2017). In this study, popular music was used to "cleanse" death from HIV/AIDS by playing certain music aimed at protecting the deceased's social identity and that of the living kin members. In cases where most people knew the deceased died from HIV/AIDS, music which depicted the inevitability of death were mostly played. These kind of music was meant to show that every person shall die regardless of what, who, how and when. In every day discourses this was expressed by the metaphor; *kera omonto emioro yaye inse erigereretie* (everybody must die given that their nose faces downwards). In this regard, the song *Kaburi* **(see Appendix 5.1)** by Vincent senior (2015) was most popular. In this song, the artist uses the metaphor of *kaburi* (grave) to show how death is inevitable to everyone whether righteous or wicked. This song was thus used to dissuade people from delving into how a person died because regardless of the type of death, death is death.

Songs which attributed the cause of death to malevolent forces such as witchcraft were also played as a way of protecting the social corporate and individual identity of the living kin members and the deceased. These kinds of songs exonerated the individual from such a death. By doing so the individual is not blamed but seen as a victim of malevolent forces. This also enabled the bereaved family to attract sympathy and compassion from other community members for their loss. The song *Papa Lolo* (**see Appendix 5.2**) by Mose Se Sengo "Fan Fan"[26] (2005) which mourns about the mysterious death of the artists' friends was commonly performed in this context.

Others songs performed were Christian songs specifically those which emphasized forgiveness of sins and salvation. These songs were observed to be performed when the deceased had earlier on after HIV/AIDS infection converted to the Christian doctrine. In

[26] Mose Se Sengo ("Fan Fan") is a guitarist, composer and band-leader from the Democratic Republic of Congo who is one of the pioneers of Congolese Soukous. He played with Francois Luambo Makiadi - Franco (TPOK Jazz) in 1968. He is popular for his Acoustic Rumba style. Though he sings mostly in Lingala, his song Papa Lolo is one of the popular songs in Kenya especially among those facing social suffering and pain.

the Christian doctrine, it is believed that if a person confesses his/her sins and accepts Jesus Christ as the savior, his/her past sins are forgiven. This conversion discards the past "spoilt identity" which is symbolized by HIV/AIDS infection and brings forth a new "good identity". This new identity symbolizes new beginning which is important in the afterlife. Therefore the performance of these Christian songs was meant to communicate to the mourners that the deceased had not experienced "permanent death" which is associated with HIV/AIDS. Instead, the deceased will inherit "eternal life" in the life after.

In this study it was, however, observed that songs which directly sang about HIV/AIDS or morality were not performed in funerals of those who died from HIV/AIDS. Instead they were performed in funerals of those who were perceived to have died of natural causes as a way of educating the populace of the dangers of HIV/AIDS. Where such songs were performed especially in the funerals of those who died of HIV/AIDS, it was meant to communicate that the living kinship members are ashamed of the deceased lived life and they did not want to be associated with it. To them such death was constructed more as a "good riddance" than "loss". The performances of such songs in this context were meant to act as a warning to the living members not to live the life of the deceased who died from HIV/AIDS related complications.

*Dealing with "death" through funeral associations*

A Funeral ceremony in most communities in Sub-Saharan Africa is one of the social activities which require a lot of resources to organize. This is because "funerals are theatres for families to compete for prestige and respect by showing off their wealth and publicity, and confirming to the norms of solidarity and respect to the dead" (Witte, 2003: 531). This partially explains why families in Sub-Saharan Africa spend more resources in funerals than treatment.

Among the Abagusii funeral ceremonies are the domain of kinship groups which form the basic unit of individual identity and social organization. Although the kinship ties are losing ground to the nuclear family due to socio-economic changes, they still remain

central in the social organization of funerals. This is because a funeral is one of the life events where the social status of the living kin is at stake than the social status of the deceased. This makes organization of a funeral a long process which requires a lot of coordination and resources.

With the advent of HIV/AIDS in the community, the social organization of funerals underwent drastic social changes. These changes were as a result of high mortality rates and the social construction of such deaths as "bad death" due to moralization of HIV/AIDS infection. This caused such deaths to attract little social support rendering funerals to be more of family than communal affairs. This was compounded by high morbidity and mortality rates which characterized the first decade of the advent of HIV/AIDS.

In response to the social problems posed by HIV/AIDS morbidity and mortality, most affected families started to mobilize resources informally based on the principle of reciprocity. This was solely meant to aid each other in funeral arrangements of their deceased kinship member. With time, however, this form of mobilization of resources became a norm among all clan members regardless of whether one was experiencing HIV/AIDS morbidity or mortality in the family. This transformation caused the mobilization of resources to take the form of informal funeral associations where each clan member was obligated to contribute towards funeral arrangements regardless of the cause of death.

The taking over of funeral arrangements by funeral associations enabled families which were bereaved from HIV/AIDS to get social support to organize decent funerals for their kin. This was made possible by the fact that the cause of death was not a determinant in the mobilization of resources. As a consequence, the bereaved families were not obligated to disclose the cause of death to non family members. In case they wished to do so, their word of mouth on the cause of death was taken as factual. This provided the bereaved families a leeway to conceal the cause of death of their loved one.

As observed in this study, funeral associations are integral actors in the organization of funeral ceremonies for clan members. Given the fact that they are based on the principle of reciprocity, clan members who reside in urban areas have also formed similar associations. The role of these urban funeral associations is mostly "to bring the corpse of their clan member back home[27] for a decent burial" as shown in **Figure 5.1.**

**Figure 5.1: Clan members preparing to transport the remains of their member "home"**




As shown in **Figure 5.1** there were specific vehicles which were hired by clan members to transport the remains of their kin from urban to rural areas "home". The use of these specialist vehicles was a symbol of status to both the living and the deceased member. As observed in this study, the use of these specialist vehicles was more pronounced where death was mostly construed as "bad death". These specialist vehicles in this context were meant to replace the eroded social status as a result of "bad death" with material symbolism status. Material symbolism in this case signified life achievements of both the

[27] See social construction of home in **chapter three**

living members and the deceased as evidenced by the ability to afford the services of specialist vehicles. This affordability also signified a "decent" funeral.

*"Celebrating Lived Life" and not mourning*

Traditionally among the Abagusii whenever death occurred, it was a norm for the bereaved family to receive emotional and social support from community members during the mourning period. For example, it was obligatory for community members to provide food to the bereaved family and other mourners. However, with HIV/AIDS, this support was threatened because of fear of contamination and associated stigma of being identified with a HIV/AIDS bereaved family. This caused mourning to be more of a family than a communal affair, thus threatening the ability of the former to accord a decent funeral to their kin. A decent funeral service in this context is symbolized by the number of people attending the service. A well attended funeral, for example, was construed as a decent funeral[28].

To deal with the threat of not giving a decent funeral service to their kin, most bereaved families reinvented traditional mourning to be a "celebration of life" of the deceased. This reinvention was more to do with overcoming the structures imposed on traditional mourning by HIV/AIDS. For example, traditional mourning required communal social support and was hinged on the type and cause of death. Celebration of lived life on the other hand, was individualized (did not require communal social support) and centered more on lived life achievements of the deceased.

The reinvention of traditional mourning to "celebration of lived life" enabled the bereaved family to manage death from HIV/AIDS through silence and concealment. This was achieved by primarily focusing on the individual's lifetime achievements. This makes death, its cause and type secondary.

[28] A well attended funeral service is believed to reconcile the spirits of the deceased and death. Also it helps the deceased's spirits to be in harmony with the living members.

As found out in this study, the "celebration of lived life" was enabled by the processes I refer to as "*commercialization*" and "*technolization"* of mortality. *Commercialization of mortality* refers to the use of monetary resources by the bereaved families to procure specific services from "professionals" in funeral organization of their departed kin with the sole purpose of meeting specific subjective goals. *Technolization of mortality* also refers to the use of modern technology by the bereaved family to attain specific subjective goals in relation to the death of their kin. In both definitions, specific subjective goals refer to warding off of social threats imposed by death from HIV/AIDS on the corporate social status and identity of the living family members.

Commercialization of mortality takes many forms depending on the social threat a particular bereaved family finds most problematic. As observed in this study, the most common social threat was having a few people attending the funeral service. To deal with this threat, most families procured catering and hospitality services from the "professional groups" to meet this need. Provision of catering and hospitality is used as a bait to attract many people to attend the funeral service as they are assured of good food and entertainment[29]. To achieve this, it was observed that funeral attendees were treated as "visitors" who have come to "celebrate the lived life" of the deceased and not "mourners" as shown in **Figure 5.2.** As noted in this study, catering and hospitality services were the major social indicators for measuring a "decent" funeral service.

[29] People's purchasing power for basic needs has been on a declining trend since 1980s when Kenya implemented the structural adjustment programs (SAPs) in response to the debt crisis occasioned by the oil crisis of 1970s. These programmes entailed fiscal discipline through limiting budget deficits by cutting down on agricultural subsidiaries and social welfare services. This was compounded further by liberalization of the economy. These policy changes increased poverty levels especially in communities which depended on agriculture as the main means of livelihood, such as the Abagusii. This period also coincided with high morbidity and mortality due to HIV/AIDS. Therefore attending funerals to "celebrate the life of the dead person" become a strategy of daily survival.

**Figure 5.2: Provision of hospitality services at a funeral**




The desire to "celebrate lived life" has also led to professionalization of some services which were hitherto provided by the community members for free. For example, the digging of the grave which was done by clan members has been taken over by "professional grave diggers" at a fee. In these new changes, digging of graves is *personalized*[30] to the bereaved family preferences and taste as a way of affirming their social status and that of the deceased member.

The commercialization of mortality was also noted to cause the development of new material culture associated with death from HIV/AIDS. This new material culture[31] was in the form of printing of T shirts with images of the deceased. Close kin members also wear uniforms during the funeral service (**See figure 5.3)**. This was aimed at affirming group solidarity and "preservation" of memories of the dead which were under threat.

[30] Personalized as used in this context refer to digging (making) the grave in such a way that meets specific subjective standards. For example, some graves are cemented and decorated with glittering tiles as a symbol of high status of the deceased and living kinship members. Important to note also that this personification also apply to other materials used in funerals such as coffins.

[31] In recent times funeral entrepreneurs have developed providing all materials needed to organize "decent" funeral.

Other forms of new material culture include the use of white instead of red ribbon in decorating vehicles used by mourners to symbolize the celebration of life. Red ribbons in the community are a social representation of risk and death. In illness discourses, risk and death is a metaphor of HIV/AIDS. Therefore when used in the case of death from HIV/AIDS, it is socially taken as a confirmation of the exact cause of death. To camouflage this, kinship members preferred to use white ribbons which symbolized celebrations of life achievements.

**Figure 5.3: Affirming group solidarity and "preservation" of memory of the death**




In this study modern technology (print and electronic media) was also found to be used subjectively to promote the concept of celebrating life. As observed, obituaries in mass media (both print and electronic) revealed that the language used in death from HIV/AIDS promoted themes of death resistance and self-actualization with no reference to actual description of biophysical processes. In this regard, euphemisms such as

"*promotion to glory*[32]" were used in reference to death and more emphasis put on individual biography, accomplishment and personality. This was unlike in non stigmatizing causes of death such as road accidents where death and its cause were emphasized as demonstrated by the extract of an obituary in one of the local daily newspapers[33] during fieldwork:

> *We the family of Mr. YY are saddened to announce the* ***untimely death*** *of our beloved brother Mr. WW while* ***undergoing treatment*** *at MMM hospital from* ***injuries sustained from a tragic road accident*** *which occurred in the morning of* ***date/month/year*** *on his way to .....*

*Technologizing mortality* was also evidenced in printed eulogies. As observed, eulogies of those who died from non-stigmatizing illnesses were detailed and described the illness trajectory such as: the kind of illness, treatment strategies and medical practitioners who attended to the deceased, a discussion of complications from medical procedures, the strengths and conditions of the deceased during each phase of illness trajectory, level of pain, level of consciousness at each particular period, attempts of resuscitation and precise time of death. However, these details are rarely provided in case of death from HIV/AIDS. Instead a chronicle of important biographical achievements of the deceased's life is enumerated in detail. A very small section is dedicated to describe the actual cause of death as demonstrated in the following purposively edited eulogy extract[34]:

[32]Euphemisms such as "promotion to glory" are used in this context to demonstrate triumph over death. This triumph is further reinforced by lived life achievements as enumerated in the individual biography, and accomplishment.

[33] This is a death announcement of one the community member in the study site. I have purposively omitted finer details of the advertisement such as the actual names of people mentioned, name of the daily newspaper and date. This was done as a way of respecting the privacy of the bereaved family. As experienced during the reflexivity exercise, most research participants were more concerned with their own privacy and that of their deceased kin.

[34] The eulogy has purposively been edited in order to protect the privacy of the bereaved family.

**Birth**

*Our beloved brother, Mr. DDD was born to the late Mr. -----and Mama ----- on date/ month /year . He was the first born son and was named after his grandfather who was a great teacher and administrator.*

**Education**

*Our brother started formal schooling in 19---- at NNNG Primary School. Due to his brilliance he was promoted from class one to three in his first year of school. Despite this, our brother continued to perform well in subsequent classes. Actually he used to top in his class. In his national examination of class eight, he was among the top fifty nationally and was top in our district. This enabled him to join WWW national high school under the generous scholarship of TTT foundation which sponsors only brilliant students. In his high school he performed very well and won many merit awards. He was appointed as the school head boy. He passed very well in the National examinations and was among the top hundred students nationally. His excellent performance won him a scholarship to------University to pursue a course in medicine. This is one of the best universities in the world. At the university, he won several awards. After his first degree he won another scholarship for masters. DDD was academic giant but very humble. That is why he offered to mentor many students from this area academically. Through his mentorship many students from this area joined our public universities.*

| ***Pictures showing DDD receiving various merit awards*** |
| --- |
| |

**Family life**

*DDD was a staunch Christian despite his academic prowess. He wedded Ms------- the pearl of his heart in 19….. In their marriage life, they were blessed with three children, two sons, QQ and RRR and a daughter NNN. QQ and NNN are schooling in Europe and*

*NNN is BBB National high school.DDD and his family rarely missed church service whenever he was at home visiting is family. He helped our church initiate many projects.*

| ***Pictures of the family in various important occasions*** |
|---|

**Occupation**

*DDD has worked with many national and international agencies in the field of medicine. He was one of the best doctors in the country. In his professional life, he had won many awards from international agencies for is contribution to alleviation of diseases. At the time of his death, he was the regional director of ……International agency.*

| ***Pictures of DDD interacting with very important people in the course of his professional work*** |
|---|

**Sickness**

*DDD has never experienced any serious illness. It is only one week ago when he was admitted at HHH private hospital. Unfortunately he passed on while undergoing treatment.*

*We loved you DDD but God loved you most.*

As noted from the above eulogy, the family is emphasizing on biographical achievements and moral virtues while muting the illness trajectory of the deceased. This is meant to morally reconstruct the threat of death from HIV/AIDS on living members through concealment. This shows eulogies are rituals are the products of the mores and values of the society they originate and therefore they are constructed according to socio-cultural context (Stark, 2005)

*Buried as a Christian*

In Kenya, HIV/AIDS has been socially constructed as a disease for morally deviant people. This is because it is transmitted mainly through heterosexual contact (Masita, 2011), and therefore people with the disease are viewed as irresponsible, immoral or promiscuous. Because of this, HIV/AIDS is seen as bringing about a "bad" or an undignified death.

To deal with this social construction of death from HIV/AIDS, most bereaved families were observed to adopt a "christian burial" for their kin. A Christian burial entails non observance of traditional rituals associated with death as a way of achieving the following social functions: one, given the fact that Christianity is mostly associated with morality; a Christian burial becomes a social approval of good morals of the deceased in lifetime. This is because Christian burials are only accorded to those who are Christians – a metaphor for morality; two, the Christian doctrine believes in forgiveness of sins. Therefore, a Christian burial becomes a symbol of moral purity of the deceased. Consequently, bereaved families were observed to prepare two eulogies, secular and non-secular. Secular focused on the material world and non-secular on Christian life of the deceased. In funerals, non-secular eulogies were given more prominence.

The desire for bereaved families to accord their deceased member a Christian burial was observed to have two profound impacts on gender relations and social organization of funerals. On the latter, it was observed that it has influenced most burials in the community to be carried out on Fridays. This is meant to allow Christians[35] who worship on Saturdays and Sundays an opportunity to attend the funeral services. Other days of the week are taken as working days.

Funerals have also become a hallmark of remarking gender relations. As observed in this study, women who hitherto played peripheral roles in funerals, have used christian burials as sites for contesting power from men in the organization of funerals. This contestation

[35] Seventh Day Adventist and Catholic are the two dominant denominations

has been made possible through various women church groups[36] which try to take a leading role in organizing funeral services of their members. This was observed to put men under a lot of pressure to protect their cultural role as community leaders leading to confrontation and sometimes withdrawal of their social support.

However as noted in this study, confrontation and threats of withdrawal of social support by men did not deter women from taking a leading role in their fellow women's funeral. This was because women had their own resources from their church groups to organize funerals of their own without depending on men who are culturally the custodian of community resources. This has forced men to include women in the organization of such funerals. This inclusion is, however, noted to be a tactic by men to protect their masculinity which is threatened by women taking over their traditional role of organizing funerals due to their economic power. This is achieved by men using this inclusion to create a public impression that they are "still in charge" of their cultural roles and women are there as "helpers".

*"Witchcraft" not HIV/AIDS*

In many African communities, the discourse of witchcraft has been used to account for illness, disease causation and etiology (Tenkorang *et al* 2011). In HIV/AIDS, for example, witchcraft accusations have been used to account for AIDS related illnesses and death especially in communities experiencing socio-economic changes (Masese, 2011; Thomas, 2008). In such communities witchcraft narratives are used to provide a socially acceptable explanation for illness as a way of positively influencing the social identity of an ill person.

In this study, it was observed that some HIV/AIDS bereaved families used witchcraft narratives to conceal the cause of death as a way of protecting their corporate social identity and that of the deceased. This concealment was achieved by exploiting the

[36] Most churches have encouraged women to form women groups not only for fellowship but also for socio-economic empowerment. For example among the Catholics there is "mama kwa mama" (woman to woman) groups which helps women to save money as a group as a way of empowering themselves. These groups also aid their members who are experiencing any problem.

principles of witchcraft in relation to illness and death among the Abagusii. According to Masese (2006), illness caused by witchcrafts defies all forms of treatment. Such illness is caused by human actors due to jealousy and the belief that witches exhume the person whom they have killed so that they can use his/her body to cleanse themselves.

As noted in this study, where a witchcraft narrative was used to account for a death, the bereaved family gave a detailed account of the illness trajectory and the corresponding illness management practices. In doing so, the family emphasized how the illness defied all the efforts of alleviating it by giving details on how treatment for each episode of illness was done, where and who was involved. In each illness episode, the family will emphasize how each illness episode was successfully alleviated but recurred again. This narration was given a lot of importance for it helped to justify that the illness under question was not natural but was caused by human actors. In illness etiology among the Abagusii, natural illnesses are supposed to be alleviated through conventional means which are either biomedical or ethno medical. Those which defy this are constructed as caused by malevolent forces "witchcraft".

Apart from a detailed illness trajectory, the family would further provide a detailed account of the social circumstances which preceded the onset of the illness. These accounts would delve so much on the social relationships of the deceased with close kinship members especially after perceived successful breakthrough in life[37]. This was meant to show that the onset of the illness was a result of jealousy (main motivation of witchcraft). In addition the focus on close kinship members is because of the belief that the impact of witchcraft is only effective among those who are related by blood (Masese, 2006).

After justification of the witchcraft narrative, the bereaved family would engage in coping strategies associated with witchcraft as a way of fortifying their claims. As

[37] This refers to the positive personal development such as getting a job, building of a house etc

observed in this study, some families would use *Sungusungu*[38] to banish those who are alleged to have caused the death by killing/lynching them, destroying their properties or ex-communicating them from the community. These actions by *Sungusungu* would help the family to conceal the exact cause of death by blaming it on "the witch".

In addition, other families would destroy the body of the deceased by corroding it with very strong acid once it is lowered into grave[39]. This is meant to prevent its exhumation by witches. Although this action is based on the belief on witchcraft relation to death causation, in the case of death from HIV/AIDS it meant to confirm to the public that the person died a good death. This is so because it is believed that witches do not exhume bodies of those who died of stigmatizing illnesses or "bad death".

**Summary and Conclusions**

This chapter discusses the socio-cultural meaning of death from HIV/AIDS. Based on social and moral discourses as found in the traditional and Christian religious paradigms, death from HIV/AIDS is constructed as a "bad death", "social death", and "shameful death". This is because such death is perceived as a social threat to the regeneration of the community through social reproduction and it negatively affects individual and corporate social identity and solidarity of group members.

Although death is biomedically an individual experience, in non western communities such as the Abagusii, it is collectively experienced. This is because individuals are not perceived as autonomous but a unit in the collective. This means that what happens to an

[38] Sungusungu is a vigilante group comprising of young, uneducated and unemployed youths. It is a non state but quasi official system of justice which was introduced into the community in 1990s by provincial administration to curb crime. Although the group was credited for stamping out crime in the initial period, they were later accused of human rights violations. As a consequence, the government outlawed them. In order to regain legitimacy among community members, the group transformed itself into a community policing unit with a sole purpose of policing social morality. In this context, policing social morality includes dealing with witches who were labeled as social deviants. For further details see Masese *et al* (2012): The genesis and evolution of Sungusungu vigilante group among the Abagusii ethnic group of Kenya. *Elixir soc.scie 42(2012): 6485-6492*

[39] This action of corroding death bodies with acids was observed to be gaining currency throughout the community albeit with subjective reasons. I postulate that in the near future,the Gusii community will adapt cremation as a means of disposing bodies. Although this initial step is being influenced by coping with witchcraft claims, other factors such as high population growth and the rapidly diminishing family land for burial will make this practice easily adaptable.

individual affects other members. Consequently, the social threats posed by death from HIV/AIDS do not affect the individual only but also other group members. As result the living kinship members embark on various strategies which aim at moral reconstruction of death from HIV/AIDS in order to protect their corporate social identity and solidarity.

# CHAPTER SIX

# DYING FROM HIV/AIDS AND ITS "PREVENTION" USING ABC STRATEGIES

## Introduction

This chapter discusses how the social construction of death from HIV/AIDS influences the construction and adoption of HIV/AIDS prevention strategies namely; abstinence, being faithful and condom use. In particular, the chapter discusses how these prevention strategies aid in achieving life projects at individual level especially attaining parenthood which is an important factor in attaining a "good death" as emphasized in the cultural belief systems.

## Parenthood and HIV/AIDS

It was a sunny Saturday morning when I went to visit 30 year old Ms. Nyabiage who was popularly known as "madam" due to her profession as a primary school teacher. Nyabiage had moved to a different town after her father denounced her because of her HIV seropositive status. In the new town she was not well known as most of the time she kept to herself. She strictly adhered to her daily schedule which involved going to her place of work in the morning and going back to her house in the evening from Monday to Friday. On Saturday she would wake up at around 9am, take breakfast and do general cleanliness in her house until 3pm. After that she would go to the nearby market and do shopping for the following week. On Sunday she would attend mass and spend most of the afternoon preparing her teaching notes.

On this particular day Ms. Nyabiage was eager to meet me. This was not because we had some important issues to discuss, but rather to honor past failed appointments due to unavoidable circumstances. In the course of my fieldwork, we had met a few times and she saw me as a friend. She had developed trust in me. As I knocked at her door, she opened it instantly. She then hugged me tight as if i was one her best friends. She then ushered me into her sitting room. As I sat down, she dashed to the kitchen to prepare lemonade. The sitting room was neatly organized as if everything was standardized to fit

in. From the imported leather sofa set to the latest 40 inch digital television set mounted on the wall, all depicting a person living life to her fullest. At the far right corner, just next to a big fridge was a big music system which was booming soft melodious music of Sam Mangwana- *Furaha ya bibi*[40] (1986) which literary translates as "the happiness of a woman". This music seemed to have been programmed as it was the only music which was playing. This created curiosity in me, given that such music genre "Rhumba" is popular among the older people. I expected her to be playing either the latest secular or non secular music. I took keen interest in the song as it boomed repeatedly:

| **Kiswahili** | **English** |
|---|---|
| *Wandugu wapenzi* | My dears brothers (sisters) |
| *Mazungumzo yangu Sio kubwa sana* | What I am saying is not a lot |
| *Wandugu wapenzi* | My dear brothers (sisters) |
| *Yale ninayoimba sio ya ajabu* | What I am singing is not mystery |
| *Ukiyafikiria ni muhimu sana* kwa maisha | If you think about it, is important for life |
| *Wandugu wapenzi* | My dear brothers (sisters) |
| | |
| *Furaha ya bwana ni kuwa na mwanamke* | The happiness of a man is to have a wife |
| *Ukiwa peke yako hauma maisha* | if you are alone you have no life |
| *Baada ya kazi ukirudi nyumbani* | After work when you go home |
| *Hauna makarabisho wala usaidishi* | No one is there to welcome or help you |
| *Hakuna kijiko wala sahani* | There is no spoon or plate |
| *Ooh furaha ya bwana ni kuwa na bibi* | Ooh the happiness of a man is to have a wife |
| | |
| *Furaha ya bibi yeeee x2* | The happiness of a woman |
| *Ni kuwa na bwana* | Is to have a husband |
| *Ukiwa peke yako hautaheshimiwa* | When you are alone you are not respected |
| *Kila wakati huchokeshi juu ya urembo yako* | *Ev*ery time you are teased about your beauty |
| | |
| *Ukiitwa bibi ya Fulani* | When you are someone's wife |
| *Ni heshima kubwa* | It accords you respect/dignity |
| *Ukiwa mwembamba au mnono* | Even if you are slim or big |
| *Heshima zote ni sawa* | This respect or dignity is most important |
| *Ooh furaha ya bibi ni kuwa na bwana* husband | *O*oh the happiness of a woman is to have a |
| | |
| *Wandugu wa bwana wandugu wa bibi* | My dear gentlemen, my dear ladies |

[40]Sam Mangwana is a Congolese musician born in Kinshasa, Democratic Republic of Congo in 1945. He was a member of Francois Luambo Makiadi's Band TPOK Jazz and Tabu Ley Rochereau's band African Fiesta Band. He is the Band leader of his Bands, Festival des Maquisards and African All Stars. In Kenya, he is popular because of his Kiswahili song: *Furaha ya bibi* (https://www.youtube.com/watch?v=B3LKOIyoxSA)

| | |
|---|---|
| *Wandugu wa bibi wandugu wa bwana* | My dear ladies, my dear gentlemen |
| *Kuwa na mpendwa ni muhimu sana* | To have a partner is very important |
| *Wakati wa shida nimasaidiano* | You will assist each other when in trouble |
| *Ikiwa usiku au mchana* | Either at day time or night. |

The more i listened to the song, the more I reflected on what it meant to be an unmarried as a woman? Does it have the same meaning in the case of a man? As I engrossed deeply in these questions, my friend came to where I was seated with two cups of lemonade. We tossed to our friendship and started chatting how life had been since we last met.

Ms. Nyabiage opened up about what she had been undergoing. In her work place, a number of her colleagues were asking why at her age she was still single and with no lover. Initially she took it lightly, but with time, even her church members started probing her why a well off lady like her was not married. To deal with this pressure, she got into a relationship with a young man who was working as a banker. To her, dating this young man was a tactic of deflecting the many questions about her sexuality as a woman. To the young man, it was an opportunity of engaging in a relationship which would lead to marriage and starting a family. These divergent interests, though motivated by cultural expectations of men and women in the society, are what created a dilemma for Nyabiage due to her HIV seropositive status.

Nyabiage's dilemma is borne of the fact that she must get married and bear children for her to attain a proper identity and status as a woman. However, this is jeopardized by her HIV seropositive status. Therefore, her listening to Sam Mangwana's song "*Furaha ya bibi"* is ironically a way of dealing with her social suffering and pain as mediated by social institutions, global systems and culture (Wilkinson 2005; Kleinman *et al* 1997). This is the dilemma she wanted to share with me. This dilemma is not restricted to her, but also to most young people who are living with HIV.

Among the Abagusii parenthood is regarded as *sine qua non* for attainment of the full status and identity of a "complete person" in the community. This means that having children is not only a means of attaining individual personhood but also a fulfillment of

one's obligation to kin and community. Consequently, getting married and having children is a cultural obligation which everyone aspires to fulfill. However, this process is fraught with many health and social obstacles especially among those who are HIV positive. This is because the epidemic lies on the pathways of biological and social reproduction (Setel, 1999). As a consequence, the epidemic intersects with social reproduction anxieties and the collective sense which moralizes it. This makes the expectations of social reproduction acute among people living with HIV because the stigma associated with HIV/AIDS is closely tied with widespread perception of social and moral crisis- a metaphor for HIV/AIDS (Smith *et al* 2010).

In this study, it was found that those who were living with HIV were eager to marry/get married and have children. This was because it accorded them not only an opportunity to lead normal lives but also acted as a means to mitigate the social stigma associated with the disease. A 31 year old farmer Mr. Ochomba elaborates:

> *After my wife's death, I was very much stigmatized. People avoided me in social places because of my HIV seropositive status. The constant humiliation made me to move to an urban centre with my two young children. While in town I started a relationship with one single mother who was residing next to our compound. I did this because of the fear that people would start probing me why I was a single father and the where abouts of my wife. I did not discuss my past life with her, nor did she. Six months later, she conceived and we started living together as husband and wife. We have been living our normal lives since then.*

As noted from Mr. Ochomba's narrative, a successful marriage and childbearing among those who are HIV seropositive is inextricably tied to protecting their social reputation by camouflaging their HIV seropositive status to avoid stigma. This is because marriage and childbearing fulfills the obligation of social reproduction which directly contests the lay people's beliefs that those infected by HIV/AIDS cannot get married and have children.

These beliefs were common during the initial period of HIV/AIDS but they still form everyday discourses of HIV/AIDS and social reproduction despite much improvement on its treatment.

Mr. Morara, a 28 year old HIV seropositive university graduate got married and begot children as a way of securing his position as a man in the community. He explains:

> *After failure to be recruited as a policeman due to my HIV seropositive status, I decided not to get married nor have children. However, as time went by, many people started pressurizing me to get married as I was getting old. In social places I was ridiculed even by young people who had just married that I was not man enough to sit with them. Some were mocking me that if I was impotent, i should just marry and they could help me sire children on my behalf. My own parents complained that they needed grandchildren. With this pressure, I realized that my status as a man was being threatened. I therefore decided to marry.*

Morara's sentiments were shared by Ms. Nyabiage, the 30 year old primary school teacher. She explains:

> *….many people questioned why I was single. Some people especially married women were very much uncomfortable when I interacted with their husbands. I became a marked person especially among the married women. In my place of work, I lost respect not only with my colleagues but also parents. They saw me as a bad influence to the girls in society.*

A critical look at Mr. Morara and Ms. Nyabiage's narratives show that women suffer more for failing to engage in parenthood than men. This is because their failure is not only seen as a risk unto themselves but to other people. For example, Ms. Nyabiage was seen as a risk by married women because of the strong presupposition that unmarried

women are not constrained in their sexual behaviour. However among men, this risk is restricted to the individual person. This means that a woman who is not married and is living with HIV suffers more than a man with the same status.

Ms. Nyakara, a 35 year old widow was inherited by her brother-in-law after her husband's death in order to secure a relationship with kin members of her husband. She sired a male child out of this relationship. This was important in protecting her young family from being disinherited:

> *At the time of my husband's death I had five girls. So definitely I did not have an heir as per our traditions. I was also being blamed for my husband's death by his relatives. Life was so hard for me and my children due the mistreatment we got from my in-laws. The younger brother to my husband wanted to start a sexual relationship with me as a way of propagating my husband's lineage. I refused his advances. After this, my late husband's kin were very hostile to me. They even started using some of my properties without my consent. I sought assistance from the local government administrators but nothing changed. Due to this pressure, I gave in to his advances in order to get protection from him. After a while I conceived and gave birth to a son. This made me to be respected and recognized among members of my late husband's family members. My troubles ended.*

Mr. Nyamweya, a 34 year old long distance truck driver also narratives:

> *After I was diagnosed with this disease I lacked love or companionship. My wife was too busy for me. She seemed to have nothing to do with me. So I had to force her to conceive as a way of securing our marriage relationship. After this she became caring and loving*

The need to perform the role of parenthood among those infected by HIV/AIDS was found to be major. This is because it is seen as a social marker of attaining the culturally expected life project goals, thus lessening the limitations imposed by being HIV seropositive as elaborated by 30 year old Ms Kemunto:

> *As a single woman, it is difficult to understand the pain of dying without leaving behind your own child. This is a double tragedy since I am not married and i have AIDS. When i die, i will be buried like a dog, despite my good education, job and investments! I have tried dating a number of men but once they discover I am HIV positive they run away. It is painful. The only option for me is to conceal my HIV seropositive status from my future suitors.*

As noted from Kemunto's narrative, getting married and having your own child is the greatest achievement which is incomparable in one's life. This means that those who die from HIV/AIDS without attaining parenthood are doubly stigmatized; that is dying without an offspring and from HIV/AIDS. Therefore, the pursuance of parenthood is seen as a means of lessening this stigma as elucidated by Mr. Juma, a 36 year old male mechanic:

> *With my HIV seropositive status, I was forced to get one more child with my wife. This not only demonstrated our "good health" but our ability to provide for our family. Before then, many people were waiting for our death. The stigma which was associated with our ill health has now lessened. I also remember our neighbor who succumbed to this illness. Before his death he had a very young baby boy. During the funeral I remember nobody talked about his illness but on how best his young family could be helped. In this regard his death was seen as an untimely death and not as bad death. This has indeed helped his family to continue to get social and economic support in their everyday life.*

Other research participants used the attributes associated with parenthood to deal with limitations imposed by dying from HIV/AIDS. Ms. Nyabonyi, the 36 year old single mother of three children, for example, observed that having children and living with HIV/AIDS has made her stronger to continue living for her children instead of worrying about dying from HIV/AIDS. This has restored her identity as a good mother who cares for her children.

Jomo, a male businessman aged 29 years also observed:

> *....the fact that i have children has been the greatest motivation for me to take care of myself and not to worry about this illness. If I provide for my children and ensure that they attain their life dreams, no one will bother with my illness. Instead my achievement as a father will be highlighted most when i die, than the spoilt identity caused by theHIV/AIDS illness.*

To some research participants, pursuance of parenthood especially mothering was found to compound the limitations imposed by HIV/AIDS on diseased bodies. For example, the fact that breastfeeding is part of a woman's identity as she enters into motherhood, she is confronted with divergent information from her socio-cultural and biomedical networks on how to care for the new born baby as a good mother. This was found to be problematic among mothers living with HIV due to the continuous and contradicting changes of biomedical policies on breastfeeding of new born babies as a means of preventing mother to child HIV transmission and cultural expectations of motherhood. These biomedical policies oscillate on whether HIV positive mothers should exclusively breastfeed their new born babies for the first six months or not (WHO, 2010; WHO, 2001; WHO, 1998). As a consequence HIV positive mothers find it difficult to perform the role of mothering to their new born babies thus injuring their identity as mothers:

> *... I thank God for answering my prayers. Since my husband and I discovered we have this illness, we prayed so much to God to have favor on us to have a son who will perpetuate our lineage. Indeed*

> *He heard our prayers and granted us a son. After birth, I did not want to infect our son. I consulted many doctors and the first doctor advised me not to breastfeed my son, which I adhered to. After three months, I visited another doctor who said I was supposed to exclusively breastfeed my son for the first six months to prevent transmission of the virus to him. These contradicting statements really traumatized me. I fear that I must have passed the virus to our God-given gift. The joy we had after giving birth to a son was no longer there. I am not sure about his HIV status because neither my husband nor I want to know* (Ms. Carren, a 26 year old).

The changes of biomedical policies on breastfeeding also problematized the role of mothering when they were synthesized with cultural expectations as illustrated by 29 year old Mrs. Okindo:

> *Culturally as a good mother, I am expected to breastfeed and at the same time introduce some solid foods to my new born baby. These actions are socially seen to enable the child to grow healthy and strong. However, for those of us who are infected, we are sometimes advised not to breastfeed or to exclusively breastfeed. This puts us in a dilemma because both cases go against the cultural expectations of mothering. For example, if I do not breastfeed my child, I am stigmatized as not being a good mother. Being HIV positive makes the stigma worse. So to protect my identity as a good mother, I am forced to feed my child as per the cultural expectations in public and in private try to adhere to medical requirements. This has drained me emotionally as I am afraid that I might have infected my child. This is the greatest problem for mothers who are HIV positive.*

Further probing of Mrs. Okindo revealed that those who faced this predicament were mostly those who had not disclosed their HIV seropositive status due to stigma. As a result, adhering to cultural expectations of mothering (breastfeeding) which are contrary to biomedical recommendations becomes a strategy of concealing HIV seropositive status. This makes pursuance of the cultural identity as a good mother to be of primary concern to prevention of mother to child HIV transmission in contexts where HIV/AIDS stigma is high.

However, mothers who had disclosed their HIV status had no problem adhering to medical recommendations of breastfeeding. In this context, their actions were seen as good for the baby. 25 old Mrs. Nyankoni explains:

> *Since i disclosed my HIV seropositive status, I do not have a problem breastfeeding my son as per the doctor's recommendations. Actually many of my close friends encourage me to do so. They see me as so caring to my young boy by protecting him from HIV. This has restored my identity as a good mother.*

Implicit from these narratives, it is clear that parenthood is one of the avenues people living with HIV use to deal with limitations imposed by the disease in their lived life. However, this is fraught with many social and ethical dilemmas which arise from public health messages on how to prevent HIV infection and the social expectations and convections about how to conduct a relationship that would lead to marriage. In this case HIV positive people find it a challenge to navigate the landscape of sex, marriage and reproduction as explained by 28 years old, Mr. Morara:

> *Among most people, HIV diagnosis is a symbol of immorality and death. This means that when you are infected, the society immediately stigmatizes and labels you as a risk. So if you disclose your status to a potential marriage partner, definitely you will lose*

> *him or her. Similarly if you inquire about past sexual history of your partner, then your relationship might end. So the best you can do is camouflage your health status. Once you marry that person, and even if he/she eventually discovers your HIV seropositive status, already you shall have had sexual intimacy and your partner wont desert you.*

Mr. Morara's observation was also noted by Mrs. Nyankoni, the 25 year old graduate teacher:

> *My late husband never told me that he was on ARV until I accidentally found them while doing general cleanliness in the house. When I confronted him he readily accepted that he was using them even before we got married. He feared I wouldn't have married him if I knew he was HIV positive. However I sometime blame myself for not taking a keen interest in knowing him more……. I was blinded by the urge of getting a partner and getting married.*

As noted from Mr. Morara's and Mrs. Nyankoni's narratives, people who are HIV positive forgo safe sex practices in pursuit of marriage and parenthood. This is because unprotected sex is commonly seen both as a marker of trust and a means of meeting the cultural life project expectations especially those centered on social reproduction. In this context, sexuality and parenthood become a theatre of reconstructing the threatened individual social identity and status.

From the biomedical perspective, this can only be achieved through adhering to HIV treatment using ARV and prevention of re-infection using ABC prevention strategies. However, in everyday life this requires a lot of (re)negotiation within a particular context on how those who are HIV positive make meaning of HIV/AIDS treatment and prevention using ABC strategies in relation to pursuit of parenthood.

**Reconstructing Death from HIV/AIDS: Treatment and "ABC Prevention Strategies**

In Sub Saharan Africa, HIV/AIDS is transmitted sexually or in association with pregnancy and breastfeeding. These modes of transmission lie at the heart of biological and social reproduction which are important determinants of an individual's personhood in time and space. Most people living with HIV/AIDS are of childbearing age and face difficult choices concerning their sexuality, parenthood and family life.

In everyday life, HIV/AIDS infection affects the way people experience parenthood. As observed in **Chapter two**, it negatively impacts on their ability to have children due to stigma and discrimination, decreased sexual activity due to ill health and fear of re-infection. This problematizes the lives of those infected with HIV/AIDS because parenthood is seen as a social marker of successful achievement of the cultural lifelong project, ascribed goals and expectations. This achievement is important in determining an individual's social identity and status both in life and in the afterlife (see **chapter three**). In addition, given the fact that HIV/AIDS is perceived as a metaphor for moral breakdown which threatens not only the regeneration of the society but also individual personhood (Dilger, 2006), parenthood becomes an avenue of reconstructing their morality which is important to their social identity and status.

The availability of highly active antiretroviral therapy (HAART) and of the intervention for prevention of mother-to-child transmission (PMTCT) in most countries has changed the life prospects of people living with HIV/AIDS, creating the possibility of achieving a new life project especially that of parenthood. However, this can be effectively achieved through positive prevention which entails: practicing safe sex, avoiding other sexually transmitted infections (STIs), reducing chances of unintended pregnancy or planning safe conception and healthy pregnancy if they want to have children and reducing HIV transmission (Osborne, 2006; Gillian *et al* 2009). All these aspects of positive prevention make use of safe sex strategies such as abstinence, being faithful and condom use (ABC).

In HIV/AIDS prevention discourses, safe sex practices (ABC) are mostly promoted as a way of preventing infection among those who are not infected (Masese, 2011). This

leaves out those who are infected, yet positive prevention lies on these strategies. Therefore understanding how those who are HIV positive makes sense of these strategies in their everyday life is important as it determines how they adopt them (Masese, 2011).
In this study, safe sex practices (ABC) were interpreted to a large extent in relation to social reproduction among HIV positive people. In this context, these strategies were seen in terms of how best they aided social reproduction and reconstructed the "spoilt identity" brought about by being HIV positive, as a way of meeting culturally ascribed life projects.

In the ABC strategy, abstinence means not engaging in sexual activity. This concept is often promoted together with "delaying sexual debut", which means delaying the onset of sexual activity until marriage or in some communication programmes until one is mature enough to make good choices regarding sex. Findings from this study; however, revealed that HIV positive people saw abstinence as a strategy of increasing likelihood of conception for those who still want to get children. Mr. Juma, the 36 year old male mechanic narrates:

> *After using ARVS for almost a year, my health improved. So we saw it wise to have another child. We sought advice from a doctor who advised us that for my wife to conceive easily, we must abstain from sex for sometime in order to increase the chances of conception. We did this for almost two months. After this we had unprotected sex for about a week during which she conceived. At least now I am proud father of a baby boy. This issue of getting a son had really taken a toll on us psychologically. With this boy, I am sure my lineage will continue when i die.*

Among some research participants who did not want more children and were single, abstinence was seen as a strategy of redeeming their past immoral behaviour which led to their infection. According to them abstaining from sex was seen as a way of protecting others from being infected by them. This action of caring for others enhanced their moral

standing in the community. Ms. Nyambeki, a 29 year old former sex commercial worker with three children elaborates:

> *I got this disease when i was a commercial sex worker. I do not know how many people i infected then. This really haunts me whenever I think about it. However, since I openly disclosed my HIV status, I decided to abstain from sex completely. This has really changed the way people see me as compared to when i was an immoral. At least now, I have regained the respect and identity as a good woman and mother. I am happy about this.*

As noted from Mr. Juma's and Ms. Nyambeki's narratives, abstinence was practiced among those who had publicly disclosed their HIV seropositive status and were using it as a strategy of reconstructing their social identity and status. This was not the case among those who had not publicly disclosed their HIV status due to stigma. Among men, for example, abstinence was seen as an abnormal sexual practice and a social indicator of HIV/AIDS infection as elaborated by 32 year old Mr. Ntabo:

> *It is not normal for a man to abstain from sex. Abstinence is actually abnormal. When I discovered my HIV seropositive status, it was difficult for me to stop having sex with my girlfriends. When I abstained for some time, my close friends thought i was either sick or abnormal. Since I did not want to raise any suspicion about my Health and HIV status, I resumed my carefree life with my girlfriends.*

Mr. Ntabo's experience can be attributed to the socially constructed notion of male and female sexuality that perceives men as having an uncontrollable urge to engage in sex, while women as asexual beings (Hirdi and Jackson, 2001; Sorrell and Raffaelli, 2005). This means men who are HIV positive find it difficult to abstain from sex because it will not only injure their identity as men but also raise suspicion about their health and bring about stigmatization.

The practice of abstinence was also found to be problematic among those still pursuing life path projects especially that of parenthood. Among the unmarried young adults, sex is mostly construed as a social marker of trust in a relationship which is destined for a marital union with children. Thus abstaining from sex in a promising sexual relationship is problematic as Mr. Morara, a single university graduate aged 26 years avers:

> *To be single and HIV positive is the worst experience. The society expects you to get married and have children. Before you find a spouse, you must engage in sexual intimacy first as a way of cementing the relationship. If you fail to do so, your girlfriend will not take that relationship serious. In addition, you cannot disclose your HIV status, because she will definitely leave you.*

According to PEPFAR (2005) the "being faithful" campaign is aimed at encouraging individuals to practice fidelity in marriage and other sexual relationships as a critical way of reducing risk of HIV/AIDS infection. However, among some research participants who were HIV positive, being faithful was construed as caring and protecting your sexual partner from HIV re-infection or other sexually transmitted infections in the pursuit of life project goals. Mr. Juma, the 36 year old mechanic narrates:

> *When my wife conceived, I had to protect her from further re-infection. So I had to stick with her as my only sexual partner. Also I had to use condoms every time we had sex to prevent re-infection. This way I cared for her health and that of my unborn baby.*

Agnes, a 30 year old mother of two children also argued that being faithful, meant meeting all the cultural roles of a woman such as taking care of the family. By doing so, her identity as a good woman is enhanced regardless of her HIV seropositive status. Similarly among men, this meant performing effectively all cultural roles assigned to them such as being a breadwinner for the family. Informal discussions with those who

construed “being faithful” as meeting cultural gender roles were noted to strictly adhere to HIV/AIDS treatment therapy. This was meant to keep them in good health so that they can perform their cultural roles effectively as a way protecting their identity and status.

In this study, condom use was socially construed as a means of bearing children who are HIV free among HIV positive people as narrated by 34 year old Mr. Okendi:

> *After knowing that we were HIV positive, we really wanted to have a baby of our own who is not infected. We sought advice from a medical consultant on how best to go about it. The doctor put us into treatment because our CD4 count was very low. After about ten months our CD4 count improved. The doctor advised us to use condoms any time we had sex. This was to protect ourselves from re-infecting each other. As time went by our viral load was so low. So the doctor advised us that it was appropriate time to conceive. To make it successful, the doctor monitored the fertility cycle of my wife for about three months. During this period he told us to abstain from sex. On the fourth month, he advised us when we could have unprotected sex for one week only. With this strict adherence to the doctor's advice, my wife conceived. After this we continued having protected sex as we continued with HIV treatment. It was a sacrifice but I am happy we got a child who is HIV free.*

**Summary and conclusion**

This chapter has shown how parenthood is used by those living with HIV/AIDS as a strategy of reconstructing their threatened social identity and status as a way of attaining a “good death” as constructed in the cultural belief system. As noted, this was achieved through adoption of positive prevention strategies like using safe sex practices (ABC) in combination with HIV/AIDS treatment. This was however hindered by the cultural construction of gender and sexuality and HIV stigma.

# CHAPTER SEVEN

# SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

## Introduction

This chapter discusses the main findings generated from in-depth conversational interviews with people living with HIV/AIDS among the Abagusii. These findings are in relation to the study objectives which were; to find out the socio-cultural meanings of death from HIV/AIDS, to understand the lived experiences of people dying from HIV/AIDS and to determine how these lived experiences of dying and death from HIV/AIDS influence action towards HIV/AIDS prevention using ABC strategies. These findings are interpreted in relation to the interpretative phenomenological analysis which informed this study.

## Summary of the findings

Human beings spend much of their life trying to avoid suffering because it is perceived as a threat to their sense of self. In everyday life, suffering can be physical, existential and social. In the discourse of suffering, social scientists are more concerned with social suffering which is caused by social forces which in most cases are mediated by social institutions, global systems and culture. These forces determine how individuals make sense of their suffering and how to cope with it. In medical anthropology this understanding has been used to understand health problems by focusing on the "lived experiences" of the victims who are suffering. In this regard, this study explored how people make meaning of everyday suffering from HIV/AIDS and how these meanings influence their action towards the epidemic in their cultural context.

In this study HIV/AIDS was constructed as a symbol of disintegration of the social fabric (Schoepf, 2001). Consequently, families and individuals were struggling to interpret and counteract its disintegration effect by integrating their experiences with the illness in relation to the social, cultural and moral framework governing everyday life. In this regard, death from HIV/AIDS was found to be a site for families and individuals to

(re)negotiate and maintain social and cultural relationships as a way of dealing with the threat posed by the epidemic.

At community level, death from HIV/AIDS was perceived as a threat because it negatively impacted on the regeneration of the family and community through social reproduction and its social corporate identity and solidarity. As a consequence, such a death was constructed as “bad death”, “shameful death" and “social death” because it threatened the shared belief of life-after-death in the cultural and christian religious discourses which govern life, death and after life.

At individual level, dying from HIV/AIDS was constructed as a biographical disruption due to the limitations imposed by the illness on the individual life project. These limitations were perceived in terms of failure to meet ascribed cultural expected standards of a life project such engaging in social reproduction and performing cultural gender roles effectively. These limitations were exacerbated by moral discourses which victimized those infected by blaming them. This legitimized discrimination and stigmatization of those infected with HIV/AIDS. This has made the experiences of dying and death from HIV/AIDS to be characterized by loss and suffering.

Consequently, the socio-cultural meanings of dying and death from HIV/AIDS were found to have power to transform social relationships at individual and collective level. This shows that HIV/AIDS is a bio-social event (Robinow, 1992) that has power not only to destroy or transform, but also build and rebuild social and cultural relationships in everyday life in various contexts. At individual level, for instance, those dying from HIV/AIDS were found to calibrate new ways of living as a way of cushioning themselves from stigma and oppressive structures. This destabilizes and undermines their sense of self as existing beings. This forced them to undergo existential reorientation by making new arrangements and quests for their new life as a way of achieving a sense of cultural, social and moral belonging to their cultural social networks (Dilger, 2005; Fassin 2000).

This reconstruction of the self was achieved using various strategies such as "breaking from the past and living a virtuous life, converting the self from being HIV/AIDS patient to an expert, managing the HIV seropositive status through self denial or ambivalence and attributing their HIV seropositive status to witchcraft". The choice of each strategy was found to be influenced by its effectiveness in addressing an individual's perceived limitations of dying from HIV/AIDS. In this context, effectiveness was seen in terms of the socio-cultural benefits of HIV disclosure or non-disclosure. As noted in this study, those who that felt HIV self disclosure would help them in dealing with stigma and discrimination used overt strategies such as "converting one's self from being an HIV/AIDS patient to an expert and breaking from the past and living a virtuous life". However, those who felt that HIV self-disclosure would lead to stigmatization and discrimination used covert strategies such as managing their HIV seropositive status through self denial (ambivalence) and attributing their illness to witchcraft.

The choice of either overt or covert strategies in dealing with the limitations imposed by HIV/AIDS was also found to be influenced by gender power relationships. As noted in this study, due to women's subordinate, social and economic status relative to men, they used overt strategies which were hinged on HIV self-disclosure to protect themselves from abandonment and violence. However, men used covert strategies which were based on HIV non-disclosure as a way of protecting their social identity and status. This shows that a combination of hegemonic masculinity and perceptions of personal invulnerability act to undermine the processes of men's HIV/AIDS risk construction and appropriate behaviour change (Ganle, 2016).

At the community level, death from HIV/AIDS has transformed how a HIV/AIDS bereaved family mourns. As found out in the study, such a death was managed by silence and concealment as a way of protecting their social corporate identity and solidarity. This means that the bereaved families were more concerned with self preservation through reinvention of traditional mourning through the processes of "*commercialization*" and "*technolization"* of mortality, use of popular music, attributing such a death to witchcraft, adopting Christianity funeral rituals and making use of funeral associations.

The desire to protect the collective social identity and solidarity is because unlike in the Western communities, individuals do not exist autonomously, but as a unit in the collective. This means that death from HIV/AIDS does not only affect an individual but also the whole family, and the community. This implies that HIV/AIDS risk management strategies which are individualized and de-contextualized are not effective especially in contexts where individual behaviour is collectively determined.

The cultural and moral response to dying and death from HIV/AIDS was found to be mediated by local, national and international factors (Schoepf, 2001; Barnett and Whitesand, 2002; Farmer, 2003; Fassin, 1992; Fassin, 2002; Fassin, 2006)). For example, the initial International and National HIV/AIDS campaigns contributed greatly to stigmatization and discrimination of those infected through moralization of the disease (Gausset, 2001; Das and Kleiman, 2011). These responses were then synthesized and integrated into local belief systems about illness and death. For example, the moralization of HIV/AIDS by international and national agencies fitted into the local social construction of illness where death was classified as "bad death". This caused HIV/AIDS illness and death to be managed by denial and concealment at individual and collective levels.

Similarly, the global promotion of HIV/AIDS treatment using ART has changed the disease from being a fatal to a chronic illness. With improved access to ART, those infected by HIV are able to live longer and healthier lives. This has accorded them an opportunity to pursue their life goal projects as a way of achieving social and cultural belongingness in their social and cultural networks thus improving their social relationships. However, this social relationship is likely to be strained where a decision has to be made on who is to benefit and why from ART especially in communities where many members are infected with HIV and resources are limited (Whyte *et al*, 2004). The strain on social relationships is also likely to increase where introduction of ART is not accompanied by appropriate health infrastructure which aims at improving accessibility, adaptability, availability and affordability as a way of preventing biological resistance against the medicine (ART) which can increase death and suffering (Tawfik *et al* 2002).

As noted in this study, most people had detailed knowledge regarding biomedical information communicated by HIV/AIDS campaigns. However, the behaviour of individuals and kinship groups in dealing with dying and death from HIV/AIDS was less based on this knowledge. Instead it was based on social relationships especially on kinship relations as collectively determined by moral and social discourses governing personhood. Consequently, at individual level those who were HIV positive were subjected to "moral practice" that regarded the illness as a consequence of their individual failures thus stigmatizing them. This greatly affected their social identity forcing them to calibrate new ways of renegotiating their social identity.

As found in this study, this renegotiation integrated biomedical strategies and local conceptions of dealing with the misfortune of HIV/AIDS illness imposed limitations. The people living with HIV used ART and safe sex practices to engage in parenthood. Parenthood in this context was used as a strategy to reconstruct their identity and improve their social acceptance in the community. This shows the inseparable link between illness, treatment and people's way of life (Heald, 2003; Kotobi, *et al* 2003).

The use of ART and safe sex practices to attain parenthood was found to be affected by gender norms governing sexuality. For example, among unmarried young people, sex is mostly constructed as a social marker of trust in a relationship which is destined for a marital union with children. Thus abstaining from sex in a promising sexual relationship is problematic. This poses a challenge of negotiating safe sex, marriage and reproduction in the context where HIV/AIDS is seen as symbol of social crisis and moral decline. In this context, having children as a way reconstructing their identity superseded HIV transmission.

The association of ART with safe sex practices in relation to parenthood reveals that HIV infection has changed the context of sexuality and social reproduction decision making. As noted in this study, an individual's behaviour and reproductive decisions are influenced by his/her socio-cultural context. It is therefore unrealistic to expect

individuals to change their sexual behaviour in relation to HIV/AIDS when contextual factors are not taken into account.

At the community level, death from HIV/AIDS was found to usher in processes that led to maintenance and modification of social and cultural relationships through reinvention of rituals. As noted by Comoroff and Comoroff (1993), rituals in Sub Saharan Africa are central areas where life situations are transformed in the context of modernity. In this context, death from HIV/AIDS has brought about reinvention of traditional death rituals (Hobsbawm *et al* 1983). This has ushered in new forms of mourning which are characterized by denial and concealment such as; medicalizing dying and death, dealing with death through funeral associations, celebrating lived life instead of mourning, Carrying out christian burials and attributing death to witchcraft and not HIV/AIDS, as a way of the bereaved family protecting their corporate social identity and solidarity. However, these new forms of dealing with death fortifies stigmatization and discrimination of those dying from HIV/AIDS as it reflects hegemonic bio-power in society (Nzioka, 1996) which emphasize differences in ways of managing death from HIV/AIDS.

**Conclusion**

Implicit from research findings, it is clear that the socio-cultural meanings of death from HIV/AIDS are mediated by cultural beliefs and values of life and death as contained in traditional and Christian religious discourses, and the social relationships in everyday life in the wider social, economic and political framework. In this case, social action towards dying and death from HIV/AIDS is evaluated and synthesized in relation to the collective moral and social discourses of personhood in a particular socio-cultural context. This means that there is need to integrate cultural beliefs and values governing life and death in HIV/AIDS prevention as a way of mitigating its impact in a particular cultural context. This is important especially at this time of improved accessibility of HIV/AIDS treatment through ARV in most communities.

**Ending by being accountable to my research participants**

As I come to the end of this thesis, I do so by fulfilling requests from two of my research participants during a reflexivity exercise on my research findings. I fulfill these requests as a way of being accountable to them because I carried out this study from an ontological perspective that knowledge is best generated through sharing of experiences between the researcher and the researched in a research context. In this case my research participants and I had an equal power relationship in the generation of knowledge contained in this thesis. Therefore I am obligated to meet their requests.

The first request was from Mrs. Nyangweso a 70 year old widow who lost her only son to HIV/AIDS who asked me to ask readers of this thesis:

*A child who loses his/her parents is called an orphan*
*A man who loses his wife is called a widower*
*A wife who loses her husband is called a widow*
*A parent who loses a child is called?*

The second request was from Ms. Nyambeki, a 29 year old former sex commercial worker who after being diagnosed with HIV/AIDS reconstructed herself by "b*reaking with the past and living a virtuous life* by getting "saved". Her request was to let readers of this thesis to reflect the words of her favorite Ekegusii Christian song by Divinah Nyamwaka titled: *Natimokire* (I have rested):

| ***Natimokire* by Divinah Nyamwaka** | **I have Rested by Divinah Nyamwaka** |
|---|---|
| **Ekegusii** | **English** |
| *Rituko Erimo, nindu ase ense eye* | One day, I will pass on from this world |
| *Abaiboiri bane barere nobororo* | My parents shall mourn sorrowfully |
| *Abana baminto, barere bakweumia* | My siblings shall mourn with sorrow |
| *Ayio onsi nabe bosa* | All their sorrow shall be in vain |
| *Mbandoke amarieta, yogokumia* | They shall call me pleasing names |
| *Baganetie mbarore, korende ntinkobarora* | Wishing that I see them, but I won't see them |
| *Mbankwane buya, korende tinkoyaiwa* | They will talk good of me, but I won't hear |
| *Ebio bionsi mbibe bosa* | All that shall be in vain |

| | |
|---|---|
| *Abasani mbatebe, Twaregotera amo,* | My friends shall say, we used to sing together |
| *Abande mbatebe, arenge omwana omuya* | Other shall say, she was a good person |
| *Mbasegesege, bakorora omobere,* | They shall be troubled to see me for the last time |
| *Korende bionsi, mbibe bosa* | All that shall be in vain |
| | |
| *Abande nabatame, ekiagera ngotioka* | Others shall run away because of my stench |
| *Abande nabatebe, otiokire motindeke,* | Others will say she is stinking, bury her quickly |
| *Tinkomanya esanduku nche ndatindekerwe* | I won't know the coffin I shall be buried in |
| *Naende ntinkomanya abarache gontindeka,* | And I won't know those who shall bury me |
| | |
| *Kwana kweboria rinde ndi orakwe* | Have you ever asked yourself, when you will die |
| *Nomanyete abasani bao mbagotame* | you know your friends might run away from you |
| *Onchokera Yeso* | Repent your sins in Jesus name |
| *Noise gokwa nonye mbono iga* | So that even if you die even now, |
| *enyorere ribaga, nobogima bwa kare na kare* | You shall get eternal life |
| | |
| *Natimokire , natimokire* | I have rested, I have rested |
| *Natimokire abaibori tiga koreraI* | I have rested my parents do not mourn |
| *Natimokire Abasani tiga korera* | I have rested my friends do not mourn |
| *Natimokire Abairi tiga korera* | I have rested my relatives do not mourn |
| *Natimokire omogaka one tiga korera* | I have rested my husband do not mourn. |

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## APPENDICES

### Appendix: 4.1 In-depth Conversational Interview Schedule

### Introduction

Greetings. My name is Masita Ednah Nyanduko, a doctorate student of Anthropology at Universite de Pau et des Pays De L'Adour. I am carrying out a research on: The Socio-cultural meaning of death from HIV/AIDS among the Abagusii-Kenya. This research is part of the requirement for the award of Universite de Pau et des Pays De L'Adour Doctor of Philosophy in Anthropology. I humbly request for your participation and cooperation. All your views will be held in confidence and will by no means be used for any other purpose outside this study. Thank you.

1. Date of birth (age)
2. Gender
3. Level of formal education
4. Marital status
5. Occupation
6. How has HIV infection affected your image of self?
7. How has HIV affected your everyday life?
8. What did HIV diagnosis mean to you?
9. How does your HIV seropositive status affect your relationships with significant others in your social network?
10. How has HIV diagnosis affected your life project goals (immediate and larger life projects)?
11. How do you deal with the impact of HIV at personal and family levels?
12. What are your experiences of living with HIV/AIDS at individual level, family level and community level?
13. What does dying from HIV/AIDS mean to you? Probe the underlying reasons for the answers given.
14. At individual level, how do you deal with dying from HIV/AIDS?
15. How does the community regard people living with HIV/AIDS? Does the community perception affect the way you deal with HIV at individual level?
16. What does abstinence, being faithful and condom use mean to you?
17. How do you negotiate safe sex practices in your sexual relationships?
18. How has HIV treatment using ARVS affected your self perception?
19. How do you integrate safe sex practices and HIV treatment in your sexual relationships?
20. How has your life project influenced safe sex practices and health seeking behaviour?

**Thank you**

**Appendix: 4.2 Guiding Questions for Key Informant Interviews**

**Introduction**

Greetings. My name is Masita Ednah Nyanduko, a doctorate student of Anthropology at Universite de Pau et des Pays De L'Adour. I am carrying out a research on: The Socio-cultural meaning of death from HIV/AIDS among the Abagusii-Kenya. This research is part of the requirement for the award of Universite de Pau et des Pays De L'Adour Doctor of Philosophy in Anthropology. I humbly request for your participation and cooperation. All your views will be held in confidence and will by no means be used for any other purpose outside this study. Thank you.

1. What are the major problems facing people living with HIV/AIDS
2. How do people living with HIV/AIDs deal with these problems at both at individual and community levels?
3. What is the meaning of death from HIV/AIDS at the community level?
4. What influences these meanings on death from HIV/AIDS
5. How do these meanings influence the way the community handles death from HIV/AIDS?
6. How has HIV treatment using antiretroviral treatment affected those living with HIV/AIDS?
7. How has HIV changed the management of death in the community?
8. How has HIV treatment influenced safe sex practices?

**Thank You**

**Appendix 5.1: Kaburi (Grave) By Vincent Senior**

| **Kiswahili** | **English translation** |
|---|---|
| Kaburi | Grave |
| *Kaburi ni tajiri* | Grave is so wealthy |
| *Kaburi ni mnyang'anyi X4* | Grave is a robber x4 |
| *Tangu mwanzo wa dunia* | Right from the beginning of the world |
| *Ulipochukua Abeli* | When you took Abel the first man |
| *Hadi leo haujashiba* | Till today you are never sastified |
| | |
| *Wabaya kwa wazuri* | The wicked and the righteous ones |
| *Waliotambulika* | Who were known |
| *Kaburi uliwachukua* | Grave didn't spare |
| *Dunia yaomboleza* | The world is mourning |
| *Kwa nini hautosheki?* | Why are you not sastified? |
| | |
| *Mandela* | Mandela |
| *John Paul II, Mother Teresa, Luther King* | John Paul II, Mother Teresa, Luther King |
| *Waliopigani haki za binadamu* | Those who fought for human rights |
| *Hata Yesu mwana wa Mungu* | Even Jesus the son of God |
| *Ulijaribu kuchukua* | you tried rob |
| *Lakini haukuweza* | but you were defeated |
| *Sababu hauna hauna nguvu* | Coz you have no powers over God's power |
| | |
| *Dunia yaomboleza* | The world is mourning |
| *Wasanii wa muziki waliotutumbuiza* | The music artists |
| *Kwa midundo motomoto* | who entertained with hit songs |
| *Kaburi uliwachukua ,* | Grave you took them |
| *Watu kama-* | People like |
| *Luther Vandrose, Sura Mbaya* | *Luther Vandrose, Sura Mbaya* |
| *Pepe kale,Lucky Dube wa Reggae* | *Pepe kale, Lucky Dube of Reggae,* |
| *Michael jackson, Madilu system* | *Micheal Jackson , Madilu System* |
| | |
| *Walikufa JUU YAKO yako Kaburi* | They died because of you grave |
| | |
| Mashujaa wa dhamana wa Kenya, | Prominent heroes of Kenya |
| Kaburi ukatunyanganya | You took them |
| Mzee Kenyatta, Tom Mboya, Oginga, | Mzee Kenyatta, Tom Mboya, Oginga, |
| Wamalwa Kijana, Samuel Wanjiru | Wamalwa Kijana, Samuel Wanjiru, |
| Wangari Mathai, Saitoti, Ojode, Michuki | Wangari Mathai, Saitoti, Ojode, Michuki |
| Waliotikisa ulimwengu kwa mabaya | Those who shook the world by evil |
| Kaburi pia haukuwasaza | You did not fear them. you took them |
| Idi Amini, Sadam Husein, | Idi Amini,Sadam Husein, |
| Osama bin Laden | Osama bin Laden |
| Ghadaffi, Hitler, Musolini | Ghadaffi, Hitler, Musolini |

**Appendix 5.2: Papa Lolo By Mose Se Sengo Fan Fan**

Aah!
*Boni boni banganga babelela ndoki ee*
(Why is is it that the witchdoctors hail witchcraft)
*Butu eyindi mokolo ya bandoki bangalaka Nzambe ooh*
(when the night fall and becomes dark thats the day/time when the witches praise GOD)
*Ntongo etaini bakolola nzoto bapemi makambo eeh*
(at the sunrise they remove their Christianity cocoons to perform witch craft, it's amazing)

**Chorus**
*Aaaah, Naleli mama a na leli papa a X2*
(Am crying for my mama, am crying for my father)
*Papa lolo eeh, babwakiyo wapi ee? X2*
(Mr lolo eeh, where did they dump you?)
*Na mokili bandimaka moto te ooh*
(In this world people never accepts anyone)
*Osangalaka liaka tuka*
(never complain that you're getting a raw deal)
*Mokili leka balanda yo eeh*
(in this world mind your own business and do
what's best people will follow you later)
*Ebale ezanga mikuwa ee*
(remember that the river doesn't have a bone)
*Baboti yo kotina lingomba*
(know that you were born in the society for a reason)
*Bandoki batitiseli yo miso ee*
(the witch will be always watching you with keen eyes)

**Chorus**

*Nzambe akela mokili,*
(God created the world)
*Atiya mpema na mopepe*
(he created breathe and wind/air/ he created life in it)
*Apesa biso mpema toi mpema*
(he gave us the breathe that you breath today)
*Akela biso na Edeni*
(he created the garden of Eden for us)
*Nzoka atiya biso na bowumbo*
(whereas he caged us in slavery)
*Ntango nyioso I LOVE YOU EEH*
(all the time we have to beg for love
saying I LOVE YOU EEH)

*Na mokili bandimaka moto te ooh*
(In this world people never accepts anyone)
*Osangalaka liaka tuka*
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*Mokili leka balanda yo eeh*
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**Laboratoire ITEM EA 3002**

**École Doctorale**

**Sciences Sociales et Humanité 481**

**Université de Pau**

**et des Pays de l'Adour (France)**

# THE SOCIO-CULTURAL MEANING OF DEATH FROM HIV/AIDS: IT'S INFLUENCE ON HIV/AIDS PREVENTION AMONG THE ABAGUSII-KENYA

Présentée par **MASITA, Ednah Nyanduko**

**Pour obtenir le grade de Docteur**
**de l'Université de Pau et des Pays de l'Adour**
**(Spécialité : Anthropologie/Ethnologie)**

**Directeur de thèse : M. Abel KOUVOUAMA**, Professeur des Universités, Université de Pau et des Pays de l'Adour

**Membres du Jury :**

**M. THIBON Christian,** Professeur des Universités, Université de Pau et des Pays de l'Adour

**M. KOUVOUAMA Abel**, Professeur des Universités, Université de Pau et des Pays de l'Adour

**Mme KOTOBI Laurence-Donia,** Maître de Conférences - HDR, Université de Bordeaux

**M. MAUPEU Hervé,** Maître de Conférences, Université de Pau et des Pays de l'Adour

**Rapporteurs :**

**Mme MOULIN, Anne-Marie,** Directrice de recherche émérite CNRS, (UMR 7219/ CNRS

**M. YENGO Patrice,** HDR, IMAF, Ecole des Hautes Etudes en Sciences Sociales – Paris

## INTRODUCTION GÉNÉRALE

Le Kenya est un pays d'Afrique de l'Est au long de l'équateur et bordant l'océan Indien à l'est. Il est voisin de l'Ouganda à l'Ouest, de la Somalie à l'Est, du Sud-Soudan au Nord-Ouest, de la Tanzanie au Sud-Ouest et de l'Éthiopie au Nord. Sa capitale est Nairobi. Il a gagné son indépendance des Britanniques en 1963 avec Jomo Kenyatta en tant que premier président. À l'intérieur, il est administrativement divisé en 47 comtés, chaque comté étant gouverné par un gouverneur qui est élu au suffrage populaire tous les cinq ans. Au Kenya, le VIH / SIDA a continué d'être un problème socio-économique et médical majeur depuis son apparition dans les années 1980. La maladie est l'une des causes principles de morbidité et de mortalité, en particulier chez les jeunes qui sont au sommet de leur âge de production (Masita, 2011, Masese, 2011). Pour cette raison, la maladie a eu un impact énorme sur le développement socio-économique du pays (Kamaara, 2005, Ministère de la Santé, 2005, Kwena, 2002).

Pour atténuer les effets négatifs du VIH / SIDA, le gouvernement kenyan a continué à lancer des campagnes massives d'intervention de prévention et à élargir l'accès au traitement. Au début du VIH / SIDA, les campagnes de prévention reposaient sur le modèle de croyance de Santé, action raisonnée / théorie du comportement planifié avec l'objectif de responsabiliser les populations sur les modes dominants de transmission, les moyens d'éviter le risque d'infection du VIH / SIDA et les conséquences de l'infection par le VIH / SIDA qui est la mort. Cela était fondé sur l'hypothèse selon laquelle, les gens ne parviennent pas à adapter des nouvelles idées ou à répondre positivement aux situations risquées du fait de manque d'informations. Cependant, des études de Rugelema, 2004; Campbell, 2004 et Parker, 2001 ont établi qu'il n'y a pas de lien direct entre les connaissances et l'évitement des risques de VIH / SIDA. En effet, de plus en plus de personnes continuent d'être infectées malgré leur niveau élevé de connaissances sur le VIH / SIDA. En conséquence, les stratégies d'intervention contre le VIH / SIDA ont commencé à se

focaliser sur les facteurs structurels influençant les comportements sexuels à risque (Hunter, 2002, Campbell et al 2001) et les significations culturelles du sexe et des pratiques sexuelles dans divers contextes culturels (Chitando, 2008; 2004). D'autres études ont également porté sur les structures de prévention et les processus de formation du sens à l'égard des stratégies sexuelles et du VIH / SIDA (Masese, 2011). Le dénominateur commun de toutes ces études est qu'elles visent à rendre efficaces les stratégies de prévention du VIH / SIDA basées sur le comportement sexuel. Cependant, il y a une lacune dans toutes ces études, sur la façon dont la construction sociale du VIH / SIDA, qui est la mort, influence les actions des gens contre le VIH / SIDA dans un contexte culturel particulier.

Contrairement à d'autres décès, la mort liée au VIH / SIDA est émotive, moralisée et socialement stigmatisée. Cette moralisation est due au fait que dans des nombreuses communautés en Afrique subsaharienne, la mort par le VIH / SIDA est principalement fondée sur les systèmes de croyances dominants du christianisme et du traditionalisme comme résultant d'actes pécheresses ou d'immoralités qui constituent en soi des barrières à l'entrée dans l'au-delà. Les deux systèmes de croyance adoptent une approche puritaine de la mort où la «bonne» mort est celle qui assure la vie après la mort. La mort par ou dans des actes telles que l'immoralité sexuelle conduit les individus vers l'enfer (Elias, 1993), et même dans les systèmes de croyance traditionnels, les personnes qui meurent par de tels actes ne peuvent pas rejoindre le monde ancestral de l'immortalité.

En étudiant le sens social de la mort par le VIH / SIDA, cette étude est consciente du fait que la mort n'est pas seulement un fait naturel, mais aussi un fait social. En tant que fait social, les gens donnent un sens à la mort à travers différents discours, idéologies, structures et normes sociales au sein de leurs réseaux sociaux ou dans leur contexte culturel. Chez les Abagusii, par exemple, la mort est un processus social qui détermine l'identité et le statut individuels. Cette identité et ce statut transcendent la mort et dépendent du type de mort (Masese, 2011; LeVine, 1982). Par conséquent, étant donné que la mort due au VIH / SIDA est stigmatisée et confère à l'individu une identité gâtée, ce type de décès est perçu comme une «mauvaise mort». Par conséquent, dans cette étude, il est postulé que de telles significations de la mort du VIH / SIDA jouent un rôle crucial sur la façon dont les gens répondent et donnent un

sens aux stratégies de prévention du VIH / SIDA pour atteindre la «bonne» identité définie par la communauté. Cette compréhension est donc essentielle et tient compte du fait que dans les programmes d'intervention contre le VIH / SIDA, la mort est considérée comme un résultat final de l'infection par le VIH / SIDA.

John Mbiti (1970) dit que les Africains perçoivent l'homme selon deux parties principales: la partie physique qui, à la mort, est mise au tombeau ou éliminée, et la partie non physique qui survit et porte la personnalité de l'individu dans l'au-delà. J. Mbiti continue de dire que le monde des esprits est une copie complète du monde physique et qu'il n'est pas éloigné de ce dernier. C'est une terre de rivières, de collines, d'animaux, et ainsi de suite et les activités de ses habitants ressemblent à celles des gens de cette vie, comme travailler dans les champs, garder du bétail, établir des familles, et ainsi de suite. (Mbiti 1970: 133). Si c'est le cas, cela signifie alors que les jugements moraux employés dans la vie s'appliquent dans l'après-mort. Ceux qui meurent d'actes immoraux telles que le VIH / SIDA, dans le cadre de cette construction, ne peuvent pas entrer dans le monde spirituel. La mort du sida symbolise une sortie permanente du monde des vivants parce qu'elle représente une fin en soi. Dans cette construction, la mort du VIH / SIDA est vécue par les vivants et les mourants comme une «mauvaise» et une mort perpétuelle qui ne résonne pas bien avec la dualité ouverte / fermée de la vie et de la mort dans de nombreuses communautés africaines. Par exemple, chez les Abagusii, une bonne mort produit les ancêtres les plus importants qui protégeront la société et assureront la continuité de la lignée. La mauvaise mort, cependant, ferme celle-ci. Cette dualité ouverte / fermée par rapport à la vie et à la mort influence les actions des individus face au VIH / SIDA.

Dans la plupart des communautés d'Afrique subsaharienne, il existe peu d'études sur la mort, en particulier en dehors des domaines de la fiction et de la théologie. C'est parce que la mort n'est pas considérée comme un domaine d'étude légitime. Cependant, avec l'augmentation du nombre de cas de VIH / SIDA, la mort due au SIDA est maintenant un risque commun et un événement familier dans la plupart des communautés de l'Afrique subsaharienne. Il est donc nécessaire de comprendre comment les personnes diagnostiquées avec le VIH et la société dans son ensemble comprennent et traitent ce type de décès et comment cela influence leurs actions en matière de prévention du VIH / SIDA.

**1 - Identification du problème**

Dans le discours sur les stratégies de prévention du VIH / SIDA, la mort est toujours considérée comme un risque certain de non-adhésion aux stratégies préventives. Cependant, la façon dont les gens comprennent ce risque est rarement prise en compte dans les programmes d'intervention. Pourtant, Illich (1976) qui a examiné l'évolution historique des significations sociales de la mort en Occident affirme que dans chaque société, «l'image dominante de la mort détermine le concept dominant de la santé, et l'histoire de la mort représente l'histoire de la médicalisation de la lutte contre la mort dans le temps et dans l'espace "(Illich, 1976: 179). Par conséquent, après la médicalisation de la mort, elle signifie maintenant différentes choses pour différentes personnes, et la définition de la mort est maintenant largement une question de jugement moral plutôt qu'un fait biologique. Cela propulse donc l'impulsion pour comprendre les significations socioculturelles et les définitions de la mort par le VIH / SIDA en relation avec les actions préventives dans un contexte culturel particulier.

Selon Elias (1993), les significations sociales de la mort peuvent être localisées dans les orientations historiquement développées que les gens ont adoptées vers leurs corps. Pour Elias, les sociétés comme les individus ont des façons uniques d'accepter et de gérer la mort. À cet égard, il est de l'avis de cette étude que les personnes dans différents contextes culturels utilisent des perspectives différentes pour donner un sens à la mort du VIH / SIDA, qui influence à son tour la façon dont elles réagissent aux stratégies d'évitement des risques.

Dans les communautés non occidentales telles que les Gusii, l'individu est pris dans le collectif. Ceci est contraire à la conception de la personnalité des sociétés occidentales qui met l'accent sur l'individualisme et les frontières. Cela signifie que dans les communautés non occidentales, le risque comme la mort n'est pas vécu, anticipé et contré par rapport à une seule personne, mais à un réseau de relations sociales. Cela signifie que la mort due au VIH / SIDA n'est pas individualisée comme l'illustrent les campagnes d'intervention contre le VIH / SIDA. Par exemple, si un membre d'un groupe social contracte et meurt du VIH / SIDA, d'autres membres souffrent de la stigmatisation sociale de la maladie par association. Pour cette raison, les individus dans un groupe social évalueront le risque de VIH / SIDA différemment. Une telle évaluation mettra l'accent sur les différentes menaces associées au risque de VIH / SIDA telles que les relations sociales menacées que la mort; et adopter des contre-mesures visant à respecter

les attributs sociaux et culturels de la personnalité. Cependant, le risque mis en évidence et les contre-mesures adoptées peuvent correspondre ou non au risque de décès tel qu'il apparaît dans les programmes d'intervention contre le VIH / SIDA.

De plus, en essayant de donner un sens aux significations socioculturelles de la mort, il est important de noter qu'il y a des attentes sur la vie d'une personne (Giddens, 1990). Le sens ou le non-sens de la mort dépend donc de deux évaluations: l'auto-évaluation de la vie vécue par l'individu et l'évaluation sociétale de la personne mourante. Mais les deux visions ne sont pas discrètes, car les paramètres sociaux de l'auto-évaluation sont déterminés par la collectivité et la qui est produite socialement. Ainsi, les deux sont des expressions différentes de la même vue parce que les opinions individuelles sont tirées du discours social plus large de la mort. Cela signifie que, bien que la mort soit un processus individuel, la mort est évaluée en fonction des différentes idéologies, structures et normes sociales contenues dans un contexte culturel particulier. Par conséquent, cette étude s'est concentrée sur la compréhension émique des significations socioculturelles de la mort par le VIH / SIDA chez les Abagusii - Kenya et son influence sur la prévention du VIH / SIDA.

**2 - Les objectifs de l'étude**

L'objectif principal de cette étude était d'étudier la signification socioculturelle de la mort par le VIH / SIDA chez les Abagusii au Kenya et son influence sur la prévention du VIH / SIDA. Utilisant la théorie de l'analyse phénoménologique interprétative, l'étude a examiné les significations socioculturelles de la mort par le VIH / SIDA, les expériences vécues de la mort du VIH / SIDA et comment ces expériences vécues ont influencé la prévention de la maladie.

**3- Questions de recherche**

L'étude a cherché à répondre aux questions suivantes:

1. Quelles sont les significations socioculturelles de la mort par le VIH / SIDA?
2. Quelles sont les expériences vécues des personnes qui meurent du VIH / SIDA?
3. Comment est-ce que ces expériences influencent-elles l'action contre le VIH / SIDA?

**4- Justification de l'étude**

Un certain nombre de facteurs ont incité à enquêter sur la signification socioculturelle de la mort par le VIH / SIDA parmi les Abagusiiau Kenya et son influence sur la prévention du VIH / SIDA. Ces facteurs comprennent :

Premièrement, parmi les Abagusii, les discussions publiques sur la mort par le VIH / SIDA sont limitées. Cette limitation est provoquée par le silence public qui caractérise ces morts (Masese, 2011). Cependant, ces derniers temps, en raison de la forte incidence des décès liés au VIH / SIDA dans la communauté, un musicien du nom de Man Pepe Sagero dans sa chanson de 2011 intitulée «Omosiki N'eriogo» (la musique est la médecine) a souligné l'importance de son préparation à sa mort en vivant aux attentes de la communauté. Dans sa chanson, l'artiste fustige l'immoralité sexuelle qui conduit à la «mauvaise mort» du VIH / SIDA. La conséquence de tels décès selon l'artiste n'affecte pas seulement l'individu mais d'autres membres du groupe social à travers la stigmatisation. Bien que la chanson vise à encourager le changement de comportement sexuel, elle fait ressortir les significations sociales et la définition de la mort du VIH / SIDA. En réponse à cela, l'étude visait à interroger si de telles significations socioculturelles de la mort par le VIH / SIDA ont des implications sur les stratégies de prévention.

Deuxièmement, dans un passé récent, les annonces de décès et d'obsèques dans la presse écrite ont de plus en plus tendance à inclure des références aux circonstances du décès. Il est désormais à la mode de voir des explications telles qu'un individu «mort d'un tragique accident de la route» ou une «longue ou courte maladie courageusement supportée». Ce qui est particulièrement intéressant, c'est pourquoi les personnes endeuillées s'intéressent-elles à leur défunt ? Ces explications pourraient-elles être des réactions à la culture naturelle de la gestion du VIH / SIDA par la peur, le déni et la dissimulation, même à l'ère du traitement du VIH? Pour le démêler, cette étude devient primordiale.

Troisièmement, la plupart des études sur les programmes d'intervention contre le VIH / SIDA, en particulier ceux qui se concentrent sur la transmission hétérosexuelle, ont le plus souvent porté sur les significations sociales du sexe et des pratiques sexuelles dans différents contextes culturels. Ainsi, il existe peu d'études (le cas échéant) axées sur les significations sociales de la mort et les stratégies de prévention du VIH / SIDA. Pourtant, dans la plupart des communautés d'Afrique subsaharienne, la sexualité et la mort ne sont que des opposés de la même pièce. Par exemple, la sexualité confère à l'individu son identité sociale et son statut pendant la vie d'un individu, et la mort le fait au-delà du temps de la vie. Par conséquent, étant

donné que la plupart des études portant sur la sexualité et les programmes d'intervention sur le VIH / SIDA ont montré que les personnes réagissaient aux stratégies de prévention du VIH / SIDA en relation avec leur construction culturelle de la sexualité, il fallait se concentrer sur leurs significations socioculturelles de mort afin de déterminer si cela a une influence sur les actions des populations en matière de stratégies de prévention du VIH / SIDA.

**5- Définition des concepts**

*Des expériences vécues*

C'est l'expérience qui présente à l'individu ce qui est réel dans la vie quotidienne dans un contexte socioculturel particulier. Cette expérience consiste en une réalité sensée qui est tenue pour acquise et tend à être moins accessible.

*Discours*

Cette étude adaptera la définition du discours de Burr (2003: 6), comme «un ensemble de significations, de métaphores, de représentations et d'énoncés qui produisent une version particulière d'un événement.

*Prévention du VIH / SIDA*

Dans cette étude, la prévention du VIH / SIDA se réfèrera aux différentes façons dont les gens utilisent pour se protéger contre les menaces ou les risques de maladie du VIH / SIDA.

**6- Résumé et organisation de la thèse**

Cette étude porte sur la signification socioculturelle de la mort par le VIH / SIDA et son influence sur la prévention du VIH / SIDA chez les Abagusii au Kenya. L'impulsion de cette étude a été rendue nécessaire par le fait que le VIH / SIDA demeure l'une des causes principales de mortalité dans de nombreuses communautés au Kenya, comme en témoignent diverses études et enquêtes savantes telles que la surveillance sentinelle annuelle, l'enquête démographique et sanitaire Kenya. Enquête sur les indicateurs. En outre, dans les discours sur la prévention du VIH / SIDA, la mort reste un risque majeur. En conséquence, la mort due au VIH / SIDA est de plus en plus courante au Kenya. Cependant, les façons dont les personnes diagnostiquées avec le VIH

/ sida et la société donnent généralement un sens à ce type de décès et à son influence sur les stratégies de prévention ont été peu étudiées. Au lieu de cela, la plupart des études sur la réduction des risques de VIH / SIDA ont eu tendance à se concentrer sur les facteurs influençant les pratiques sexuelles dans divers contextes. Contrairement à d'autres maladies incurables, le VIH / sida est une maladie émotive, moralisée et socialement stigmatisée qui est principalement transmise par contact sexuel non protégé. Cette moralisation du syndrome influence inévitablement les comportements de recherche de santé. Au Kenya, il existe de nombreuses sources d'information qui permettent de savoir comment gérer la maladie chez les personnes infectées. La plupart de ces sources traitent principalement de la gestion biomédicale de la maladie sans tenir compte des systèmes de croyances des populations locales qui influencent le comportement de recherche de la santé pour les personnes infectées ou affectées par la maladie dans la plupart des communautés.

Comme le notent les constructionnistes sociaux, les gens ne sont pas de simples consommateurs d'informations qui leur sont données. Au lieu de cela, ils synthétisent ces informations en une connaissance commune partagée telle qu'elle existe dans leurs institutions, dans leur langage quotidien et dans leurs significations et leur compréhension communes. Ce savoir commun partagé est construit à travers la socialisation comme résultat de l'interaction sociale, de la négociation et du pouvoir. Cela signifie que les gens construiront leurs propres réalités sur la façon de traiter l'infection par le VIH / SIDA en fonction de leur système de croyances culturelles et des circonstances sociales et économiques qui prévalent. Ces réalités construites qui peuvent ou non être des traductions précises de la gestion biomédicale de la maladie guideront néanmoins les actions des populations. Par conséquent, cette thèse soutient que les efforts de changement de comportement qui ne tiennent pas compte de ces croyances sont voués à échouer dans la réduction de la transmission du VIH / SIDA dans une communauté donnée.

En étudiant la signification socioculturelle de la mort par le VIH / SIDA et son influence sur la prévention du VIH, cette étude a été guidée par la théorie de l'analyse phénoménologique interprétative et trois questions de recherche: quel est le sens socioculturel de la mort du VIH / SIDA? Quelles sont les expériences vécues de mourir du VIH /SIDA et comment ces expériences vécues de mourir du VIH / SIDA influencent-elles les stratégies de

prévention telles que l'abstinence, la fidélité et l'utilisation du préservatif (ABC). En répondant à ces questions de recherche, les données ont été collectées pendant quinze mois auprès de personnes ayant reçu un diagnostic de VIH, de laïcs et de leaders d'opinion tels que les chefs religieux de la communauté Abagusii au Kenya. L'étude a révélé que la façon dont les gens «donnent un sens» à la mort dépend du système de croyance dominant et des significations socioculturelles spécifiques attachées aux formes particulières de la mort.

Chez les Abagusii, tout comme la plupart des communautés d'Afrique subsaharienne, le VIH / SIDA se transmet par des relations hétérosexuelles. Cela a fait de la maladie une métaphore de la contamination morale. Les personnes infectées par le VIH / sida acquièrent une identité gâchée et doivent assumer le fardeau de nl'infection. Par conséquent, un diagnostic séropositif a été noté pour inciter une personne à se livrer à une infection par le VIH transmettant un comportement ou un comportement responsable selon la façon dont on comprend la mort imminente du VIH / SIDA et la vie présumée après la mort système. Comme il a été noté chez les Abagusii, il existe une croyance commune partagée selon laquelle la mortalité physique ne conduit pas nécessairement à la mortalité spirituelle. L'immortalité de la vie est supposée se perpétuer à travers le processus de reproduction sociale. Cependant, ce processus est menacé par le VIH / SIDA parce qu'il est principalement transmis sexuellement et pourtant la sexualité est inextricablement liée à la reproduction sociale. Cela fait de la mort due au VIH / SIDA un problème car elle menace la croyance culturelle de la vie après la mort.

Chez les Abagusii, la mort par VIH / sida est interprétée comme une «mort permanente». Les personnes diagnostiquées séropositives sont donc obligées d'utiliser diverses tactiques telles que se marier et avoir des enfants (femmes ou paternité) pour dissimuler leur séropositivité. Comme on le constate dans cette étude, les attentes de reproduction sociale sont plus aiguës chez les personnes séropositives parce que la stigmatisation associée au VIH / SIDA est étroitement liée à la perception répandue de la crise sociale et morale (une métaphore du VIH / SIDA) . Par conséquent, pour les personnes séropositives, se marier (ou se marier) et avoir des enfants leur offre non seulement la possibilité de mener une vie normale, mais aussi un moyen d'atténuer la stigmatisation associée à la maladie.

La poursuite de la reproduction sociale en tant que stratégie de rachat d'une identité gâtée a été aidée par le traitement de la Thérapie Antirétroviral (TAR) qui est assez accessible à la plupart des patients séropositifs au Kenya. Comme indiqué, le traitement antirétroviral a amélioré la santé des personnes séropositives. Cela leur a permis de poursuivre leurs aspirations individuelles et la communauté a assigné des objectifs tels que la reproduction sociale, parce que le VIH / SIDA n'est plus considéré comme une condamnation à mort certaine. Cependant, dans la poursuite des objectifs de reproduction sociale, les individus ont été confrontés à de nombreux dilemmes sociaux, éthiques et médicaux alors qu'ils essayaient de vivre leurs ambitions et de se conformer à la norme sociale. Par exemple, les patients séropositifs sont informés médicalement que les rapports sexuels non protégés sont risqués et pourtant socialement considérés comme un marqueur de confiance et d'expression de la possibilité que la relation puisse évoluer vers une union conjugale avec les enfants.

En conséquence, cette étude a révélé que ces dilemmes affectaient négativement les stratégies de prévention du VIH / SIDA, à savoir l'abstinence, la fidélité et l'utilisation du préservatif (ABC). Cela a été compliqué par la perception que le VIH / SIDA lui-même est un symbole de crise sociale et de déclin moral. Par exemple, les patients séropositifs ont trouvé extrêmement difficile de discuter de pratiques sexuelles sécuritaires avec leurs partenaires sexuels, par crainte de révéler leur séropositivité. Bien que mourir du VIH / SIDA était avant tout un problème social individuel, la mort par le VIH / SIDA était tout aussi problématique pour les membres de la parenté proche. En raison de la stigmatisation d'un proche parent mourant du VIH / SIDA et la construction de tels décès comme «mauvaise mort». Comme observé dans cette étude, les personnes qui sont mortes d'une «mauvaise mort» étaient supposées ne pas avoir de vie après la mort, ils ont donc attiré peu de sympathie publique et de soutien matériel pour des funérailles «décentes».

À la lumière de ce qui précède, les familles endeuillées ont été poussées à dissimuler la cause de la mort de leurs parents en utilisant diverses tactiques. Certaines de ces tactiques incluent, blâmer de tels décès sur la sorcellerie et par conséquent en utilisant des membres du groupe de vigilants tels que "sungusungu" pour bannir ceux qui sont blâmés pour cela. D'autres ont souligné la cause immédiate de la mort qui, dans la plupart des cas, était supposée ne pas être

liée à la maladie du VIH / SIDA. Dans certains cas, la famille transforma les activités de deuil en célébrations de la vie du défunt à travers de somptueux festins où les réussites positives du défunt au cours de sa vie étaient les seules à être soulignées par des publicités nécrologiques et des éloges funèbres.

La gestion de la mort par le VIH / SIDA à travers la culture du déni et de la dissimulation était en grande partie une réaction de peur de la stigmatisation sociale, de l'ostracisme et de l'isolement qui sont des réponses sociétales prédominantes aux personnes diagnostiquées avec le VIH / SIDA. Cette culture est encore renforcée par le système de croyances culturelles dominant et les discours des personnes laïques qui promeuvent l'idée que les personnes vivant avec le VIH / SIDA ne connaissent pas la vie après la mort. En conséquence, les personnes diagnostiquées avec le VIH / SIDA sont poussées à se comporter comme si elles n'étaient pas infectées dans le but de dissimuler leur statut séropositif au VIH. L'incapacité de ces personnes à négocier des rapports sexuels protégés les pousse à avoir des rapports sexuels non protégés, ce qui augmente la transmission du VIH.

En conclusion, cette thèse soutient que pour que les stratégies de prévention du VIH / SIDA soient efficaces, il est nécessaire d'incorporer les croyances culturelles associées à la mort d'une maladie particulière. Ces croyances culturelles jouent un rôle important en influençant le comportement de recherche de la santé des gens. C'est parce que dans la plupart des communautés, la mort n'est pas perçue comme une fin de vie mais comme une transition vers une autre vie. Cette transition qui confère un statut élevé individuel et une identité propre dépend de la construction de la mort individuelle. Par conséquent, les personnes confrontées à la mort imminente du VIH / SIDA peuvent adopter des comportements susceptibles d'aider ou de prévenir la propagation de la maladie en fonction de la manière dont elles donnent un sens à une telle mort dans leur contexte socioculturel.

Cette thèse est divisée en deux parties. La première partie couvre le chapitre un au chapitre quatre. Dans le premier chapitre, je fournis un fondement théorique et empirique de l'étude en utilisant diverses approches théoriques qui ont guidé la recherche en sciences sociales sur le VIH / SIDA depuis son avènement. Ce faisant, le chapitre soutient que le problème de la gestion du VIH / SIDA repose sur la construction sociale du VIH / SIDA en tant que maladie

dans un système de croyances culturelles particulier et non sur le VIH / SIDA comme maladie ou syndrome biomédical. Le chapitre aborde ensuite les théories de la mort afin d'éclairer les significations socioculturelles de la mort par le VIH / SIDA et son influence sur sa gestion.

Le deuxième chapitre traite de manière critique du VIH / SIDA comme un problème social majeur au Kenya. En utilisant des récits sur la maladie des personnes vivant avec le VIH / SIDA, le chapitre affirme que le problème social majeur du VIH / SIDA dans toute communauté est la perturbation sociale de la vie sociale. Ceci est mis en évidence par l'impact de la maladie sur le projet de vie existentiel des personnes infectées où il impose plusieurs limitations de la vie sociale. Ces limites contraignent les personnes infectées à calibrer une nouvelle histoire de vie, de nouvelles valeurs et de nouveaux plans de vie qui, à leur tour, influencent la façon dont ils gèrent la maladie dans leur vie quotidienne.

Le chapitre trois fournit les informations générales sur les Abagusii. En particulier, le chapitre traite de leur terre, de leur organisation sociale et de leur conception de la vie et de la mort. Le chapitre souligne le fait que le mode de vie des Abagusii, en particulier sur les questions de la vie et de la mort, est fortement influencé par les valeurs et les connaissances que l'on trouve dans leur système de croyances culturelles. Ce chapitre permet donc de comprendre différentes constructions de personnes façonnées par la culture et la société et de façonner la compréhension individuelle de la vie et de la mort. Cette compréhension est importante parce que c'est la thèse de cette thèse que les interventions de réduction des risques et des risques comme dans le cas du VIH / SIDA sont façonnées par la culture, la société et l'histoire.

Le chapitre quatre explore les processus méthodologiques, les théories et la pratique qui ont guidé cette étude. Le chapitre en particulier explique comment le cadre théorique de l'analyse phénoménologique interprétative a influencé les choix méthodologiques et les décisions prises au cours de l'étude. Le chapitre aborde également les approches et méthodes utilisées dans l'étude : approche de l'étude de cas, sélection de l'échantillon et taille de l'échantillon, technique d'échantillonnage en boule de neige, entretiens conversationnels approfondis, interviews ciblées, enregistrement des interviews et notes de terrain. En outre, le chapitre aborde les défis du maintien d'une distance critique en tant que chercheur anthropologue émique sur un sujet sensible de la mort et de la maladie du VIH / SIDA.

La deuxième partie couvre le chapitre cinq ; le chapitre sept qui livre les arguments jusqu'aux conclusions. Au chapitre cinq, les significations socioculturelles de la mort par le VIH / SIDA sont examinées. Le chapitre affirme que la mort par le VIH / SIDA est vécue comme une «mauvaise mort» qui perturbe non seulement la vie sociale et les relations de parenté, mais aussi les pratiques traditionnelles de traitement des mourants et des décès. Pour cette raison, il existe de Nouvelles pratiques évolutives de traitement de la mort par le VIH / SIDA qui se caractérise par la culture de la dissimulation, du silence et du déni. Ce chapitre fait donc valoir que la mort par le VIH / SIDA produit de nouvelles significations socioculturelles de la mort qui nécessitent de nouvelles stratégies de gestion de  la mort.

Le chapitre six examine de manière critique l'interaction entre les significations socioculturelles de la mort par le VIH / SIDA et l'adoption de stratégies de prévention à savoir: l'abstinence, la fidélité et l'utilisation du préservatif dans les experiences quotidiennes des gens. En particulier, le chapitre discute de façon critique comment les individus confrontés à la mort imminente du VIH / SIDA négocient des questions de sexualité sans risque et de reproduction sociale, particulièrement sur la paternité et la maternité qui sont essentielles à la «bonne mort». Le chapitre traite également de la manière dont le projet de vie d'un individu influence l'adoption de stratégies préventives dans la vie de tous les jours.

Le chapitre sept discute et interprète de manière critique les principaux résultats de l'étude basés sur le cadre théorique de l'analyse phénoménologique interprétative qui a guide cette étude. Dans ce cas, les significations socioculturelles de la mort par le VIH / SIDA sont discutées et interprétées en fonction de la façon dont ells informant l'action vers les stratégies de prévention du VIH / SIDA, y compris; abstinence, fidélité et usage du préservatif dans la vie de tous les jours. Le chapitre résume ensuite les principales conclusions.

**7- Résumé des résultats**

Les êtres humains passent une grande partie de leur vie à essayer d'éviter la souffrance parce qu'ils sont perçus comme une menace pour leur sens de soi. Dans la vie quotidienne, la souffrance peut être physique, existentielle et sociale. Dans le discours sur la souffrance, les chercheurs en sciences sociales se préoccupent davantage de la souffrance sociale causée par les forces sociales qui, dans la plupart des cas, sont médiatisées par les institutions sociales, les systèmes mondiaux et la culture. Ces forces déterminent comment les individus donnent un sens à leur souffrance et comment y faire face. En anthropologie médicale, cette compréhension a été utilisée pour comprendre les problèmes de santé en se concentrant sur les «expériences vécues» des victimes qui souffrent. À cet égard, cette étude a exploré comment les gens donnent un sens à la souffrance quotidienne du VIH / SIDA et comment ces significations influencent leur action vers l'épidémie dans leur contexte culturel.

Dans cette étude, le VIH / SIDA a été construit comme un symbole de désintégration du tissu social (Schoepf, 2001). Par conséquent, les familles et les individus luttaient pour interpréter et contrer son effet de désintégration en intégrant leurs expériences de la maladie par rapport au cadre social, culturel et moral qui régit la vie quotidienne. À cet égard, la mort due au VIH / sida a été considérée comme un site permettant aux familles et aux individus de (re) négocier et de maintenir des relations sociales et culturelles afin de faire face à la menace que représente l'épidémie. Au niveau communautaire, la mort du VIH / SIDA était perçue comme une menace car elle avait un impact négatif sur la régénération de la famille et de la communauté à travers la reproduction sociale et son identité corporative sociale et sa solidarité. En conséquence, une telle mort a été construite comme «mauvaise mort», «mort honteuse» et «mort sociale» parce qu'elle menaçait la croyance partagée de la vie après la mort dans les discours religieux culturels et chrétiens qui régissent la vie, la mort et la vie.

Au niveau individuel, mourir du VIH / SIDA a été construit comme une perturbation biographique due aux limites imposées par la maladie sur le projet de vie individuel. Ces limites ont été perçues en termes de non-respect des normes culturelles attendues d'un projet de vie tel que celui de s'engager dans la production sociale et d'effectuer efficacement des rôles de genre culturels. Ces limites étaient exacerbées par les discours moraux qui victimisaient les personnes

infectées en les blâmant. Cela légitimait la discrimination et la stigmatisation des personnes infectées par le VIH / sida. Cela a fait que les expériences de mort du VIH / SIDA se caractérisent par des pertes et des souffrances.

En conséquence, les significations socioculturelles de la mort et de la mort du VIH / SIDA ont été jugées capables de transformer les relations sociales au niveau individuel et collectif. Cela montre que le VIH / SIDA est un événement biosocial (Robinow, 1992) qui a le pouvoir non seulement de détruire ou de transformer, mais aussi de construire et de reconstruire des relations sociales et culturelles dans la vie quotidienne dans divers contextes. Au niveau individuel, par exemple, on a constaté que les personnes décédées du VIH / sida étalonnaient de nouvelles façons de vivre afin de se prémunir contre la stigmatisation et les structures oppressives. Cela déstabilise et sape leur sentiment de soi en tant qu'êtres existants. Cela les a forcés à subir une réorientation existentielle en faisant de nouveaux arrangements et de nouvelles quêtes pour leur nouvelle vie afin de créer un sentiment d'appartenance culturelle, sociale et morale à leurs réseaux sociaux culturels (Dilger, 2005).

Cette reconstruction de soi a été réalisée en utilisant diverses stratégies telles que «rompre avec le passé et vivre une vie vertueuse, se convertir d'un patient VIH / SIDA à un expert, gérer le statut séropositif par le renoncement ou l'ambivalence et attribuer leur séropositivité au VIH statut à la sorcellerie ". Le choix de chaque stratégie a été jugé influencé par son efficacité à répondre aux limites perçues de la mort par le VIH / SIDA. Dans ce contexte, l'efficacité a été considérée en termes de bénéfices socioculturels de la divulgation ou de la non-divulgation du VIH. Comme indiqué dans cette étude, ceux qui pensaient que la révélation du VIH les aiderait à faire face à la stigmatisation et à la discrimination utilisaient des stratégies ouvertes telles que «se convertir d'un patient VIH / SIDA à un expert et rompre avec le passé et mener une vie vertueuse». Cependant, ceux qui pensaient que la révélation du VIH conduirait à la stigmatisation et à la discrimination utilisaient des stratégies secrètes telles que la gestion de leur statut séropositif au VIH par l'auto dénégation (ambivalence) et l'attribution de leur maladie à la sorcellerie.

Le choix de stratégies ouvertes ou cachées pour faire face aux limites imposées par le VIH / SIDA a également été influencé par les relations de pouvoir entre les sexes. Comme noté dans cette étude, en raison du statut subalterne, social et économique des femmes par rapport aux hommes, ils ont utilisé des stratégies ouvertes qui se basaient sur la révélation du VIH pour se protéger de l'abandon et de la violence. Cependant, les hommes ont utilisé des stratégies secrètes basées sur la non-divulgation du VIH comme moyen de protéger leur identité sociale et leur statut. Cela montre qu'une combinaison de la masculinité hégémonique et des perceptions de l'invulnérabilité personnelle agissent pour saper les processus de construction du risque de VIH / SIDA chez les hommes et de changement de comportement approprié (Ganle, 2016).

Au niveau communautaire, la mort due au VIH / SIDA a transformé le deuil d'une famille endeuillée par le VIH / SIDA. Comme on l'a découvert dans l'étude, un tel décès était géré par le silence et la dissimulation comme moyen de protéger leur identité corporative sociale et leur solidarité. Cela signifie que les familles endeuillées se préoccupaient davantage de l'autoprotection en réinventant le deuil traditionnel à travers les processus de «commercialisation» et de «technolisation» de la mortalité, l'utilisation de la musique populaire, l'attribution de la mort à la sorcellerie et l'utilisation des rituels funéraires. des associations funéraires.

Le désir de protéger l'identité sociale collective et la solidarité est que contrairement aux communautés occidentales, les individus n'existent pas de manière autonome, mais comme une unité dans le collectif. Cela signifie que la mort due au VIH / SIDA n'affecte pas seulement un individu mais aussi toute la famille. Cela implique que les stratégies de gestion des risques du VIH / SIDA qui sont individualisées et décontextualisées ne sont pas efficaces, en particulier dans les contextes où le comportement individuel est déterminé collectivement.

La réponse culturelle et morale à la mort et à la mort due au VIH / SIDA a été jugée être influencée par des facteurs locaux, nationaux et internationaux (Schoepf, 2001, Barnett et Whitesand, 2002, Farmer, 2003). Par exemple, les premières campagnes internationales et nationales contre le VIH / sida ont grandement contribué à la stigmatisation et à la discrimination des personnes infectées par la moralisation de la maladie (Gausset, 2001, Das et Kleiman, 2011). Ces réponses ont ensuite été synthétisées et intégrées dans les systèmes de croyances locales sur la maladie et la mort. Par exemple, la moralisation du VIH / SIDA par les agences internationales et nationales s'intégrait dans la construction sociale locale de la maladie où la mort était classée

comme «mauvaise mort». Cela a causé la maladie du VIH / SIDA et la mort à gérer par le déni et la dissimulation aux niveaux individuel et collectif.

De même, la promotion mondiale du traitement contre le VIH / SIDA en utilisant la thérapie antirétrovirale a transformé la maladie d'une maladie fatale à une maladie chronique. Avec un meilleur accès au traitement antirétroviral, les personnes infectées par le VIH peuvent vivre plus longtemps et en meilleure santé. Cela leur a donné l'opportunité de poursuivre leurs projets d'objectifs de vie comme un moyen d'atteindre l'appartenance sociale et culturelle dans leurs réseaux sociaux et culturels, améliorant ainsi leurs relations sociales. Cependant, cette relation sociale risque d'être tendue lorsqu'une décision doit être prise sur qui bénéficiera et pourquoi, en particulier dans les communautés où de nombreux membres sont infectés par le VIH et où les ressources sont limitées (Whyte et al, 2004). La pression sur les relations sociales risque également d'augmenter lorsque l'introduction du traitement antirétroviral n'est pas accompagnée d'une infrastructure sanitaire appropriée qui vise à améliorer l'accessibilité, l'adoptabilité, la disponibilité et l'accessibilité pour prévenir la résistance biologique aux médicaments (ART) souffrance (Tawfik et al 2002).

Au niveau communautaire, la mort due au VIH / SIDA a changé. Comme noté dans cette étude, la plupart des gens avaient des connaissances détaillées sur les informations biomédicales communiquées par les campagnes de lutte contre le VIH / SIDA. Cependant, le comportement des individus et des groupes de parenté face au décès et à la mort du VIH / SIDA était moins basé sur ces connaissances. Au lieu de cela, il était basé sur des relations sociales, en particulier sur les relations de parenté comme collectivement déterminées par les discours moraux et sociaux régissant la personne. Par conséquent, au niveau individuel, les personnes séropositives étaient soumises à une «pratique morale» qui considérait la maladie comme une conséquence de leurs échecs individuels, les stigmatisant ainsi. Cela a grandement affecté leur identité sociale, les forçant à calibrer de nouvelles façons de renégocier leur identité sociale.

Comme nous l'avons constaté dans cette étude, cette renégociation a intégré les stratégies biomédicales et les conceptions locales de la prise en charge des malheurs imposés par les maladies liées au VIH / SIDA. Les personnes vivant avec le VIH ont eu recours à la thérapie antirétrovirale et aux pratiques sexuelles sans risque pour s'engager dans la parentalité. La parentalité dans ce contexte a été utilisée comme une stratégie pour reconstruire leur identité et améliorer leur acceptation sociale dans la communauté. Cela montre le lien inséparable entre la maladie, le traitement et le mode de vie des gens (Heald, 2003). L'utilisation de la thérapie antirétrovirale et des pratiques sexuelles sûres pour atteindre la parentalité a été jugée affectée par les normes de genre régissant la sexualité. Par exemple, parmi les jeunes non mariés, le sexe est surtout construit comme un marqueur social de confiance dans une relation destinée à une union conjugale avec des enfants. Ainsi s'abstenir de sexe dans une relation sexuelle prometteuse est problématique. Cela pose un défi de négocier des rapports sexuels protégés, le mariage et la reproduction dans le contexte où le VIH / SIDA est considéré comme un symbole de crise sociale et de déclin moral. Dans ce contexte, avoir des enfants comme moyen de reconstruire leur identité a remplacé la transmission du VIH.

L'association de la thérapie antirétrovirale à des pratiques sexuelles sûres en rapport avec la parentalité révèle que l'infection par le VIH a modifié le contexte de la prise de décision en matière de sexualité et de reproduction sociale. Comme indiqué dans cette étude, le comportement socioculturel d'un individu et ses décisions en matière de reproduction sont influencés par son contexte socioculturel. Il est donc irréaliste de s'attendre à ce que les individus changent leur comportement sexuel par rapport au VIH / SIDA lorsque les facteurs contextuels ne sont pas pris en compte.

Au niveau de la communauté, la mort due au VIH / SIDA s'est révélée être à l'origine de processus qui ont conduit au maintien et à la modification des relations sociales et culturelles grâce à la réinvention des rituels. Comme l'ont noté Comoroff et Comoroff (1993), les rituels en Afrique subsaharienne sont des zones centrales où les situations de la vie sont transformées dans le contexte de la modernité. Dans ce contexte, la mort du VIH / SIDA a entraîné la réinvention des rituels de mort traditionnels (Hobsbawm et al 1983). Cela a inauguré de nouvelles formes de deuil qui sont caractérisées par le déni et la dissimulation tels que; Médicaliser la mort et la mort, faire face à la mort par des associations funéraires, célébrer la vie vécue et ne pas pleurer, enterré

comme chrétien et attribuer la mort à la sorcellerie et au VIH / SIDA, comme moyen pour la famille endeuillée de protéger son identité sociale et solidaire. Cependant, ces nouvelles formes de traitement de la mort fortifient la stigmatisation et la discrimination de ceux qui meurent du VIH / SIDA car elle reflète le bio-pouvoir hégémonique de la société (Nzioka, 1996).

**Conclusion**

Il ressort clairement des résultats de la recherche que les significations socioculturelles de la mort par le VIH / sida sont véhiculées par les croyances culturelles et les valeurs de la vie et de la mort contenues dans les discours religieux traditionnels et chrétiens, et les relations sociales dans la vie quotidienne. cadre social, économique et politique. Dans ce cas, l'action sociale vers la mort et la mort du VIH / SIDA est évaluée et synthétisée par rapport aux discours moraux et sociaux collectifs de la personnalité dans un contexte socioculturel particulier. Cela signifie qu'il est nécessaire d'intégrer les croyances culturelles et les valeurs qui régissent la vie et la mort dans la prévention du VIH / SIDA afin d'en atténuer l'impact dans un contexte culturel particulier. Ceci est important, surtout en cette période d'amélioration de l'accessibilité au traitement du VIH / SIDA dans la plupart des communautés.

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## APPENDICES

### Appendix:4.1 In Depth Conversational Interview Schedule

### Introduction

Greetings. My name is Masita Ednah Nyanduko, a doctorate student of Anthropology at Universite de Pau et des Pays De L'Adour. I am carrying out a research on: The Socio-cultural meaning of death from HIV/AIDS among the Abagusii-Kenya. This research is part of the requirement for the award of Universite de Pau et des Pays De L'Adour Doctor of Philosophy in Anthropology. I humbly request for your participation and cooperation. All your views will be held in confidence and will by no means be used for any other purpose outside this study. Thank you.

1. Date of birth (age)
2. Gender
3. Level of formal education
4. Marital status
5. Occupation
6. How has HIV infection affected your image of self?
7. How has HIV affected your everyday life?
8. What did HIV diagnosis mean to you?
9. How does your HIV seropositive status affect your relationships with significant others in your social network?
10. How has HIV diagnosis affected your life project goals (immediate and larger life projects) ?
11. How do you deal with the impact of HIV at personal and family levels?
12. What are your experiences in living with HIV/AIDS at individual level, family level and community level?
13. What does dying from HIV/AIDS mean to you? Probe the underlying reasons for the for answers given.

14. At individual level, how do you deal with dying from HIV/AIDS?
15. How does the community regard people living with HIV/AIDS? Does the community perception affect the way you deal with HIV at individual level?
16. What does abstinence, being faithful and condom use mean to you?
17. How do you negotiate safe sex practices in your sexual relationships?
18. How has HIV treatment using ARVS affected yourself perception?
19. How do you integrate safe sex practices and HIV treatment in your sexual relationships?
20. How has your life project influenced safe sex practices and health seeking behaviour ?

**Thank you**

**Appendix:4.2 Guiding Questions For Key Informant Interviews**

**Introduction**

Greetings. My name is Masita Ednah Nyanduko, a doctorate student of Anthropology at Universite de Pau et des Pays De L'Adour. I am carrying out a research on: The Socio-cultural meaning of death from HIV/AIDS among the Abagusii-Kenya. This research is part of the requirement for the award of Universite de Pau et des Pays De L'Adour Doctor of Philosophy in Anthropology. I humbly request for your participation and cooperation. All your views will be held in confidence and will by no means be used for any other purpose outside this study. Thank you.

1. What are the major problems facing people living with HIV/AIDS
2. How do people living with HIV/AIDs deal with these problems at both at individual and community levels?
3. What is the meaning of death from HIV/AIDS at the community level?
4. What influences these meanings on death from HIV/AIDS
5. How do these meanings influence the way the community handles death from HIV/AIDS?
6. How has HIV treatment using antiretroviral treatment affected those living with HIV/AIDS?
7. How has HIV changed the management of death in the community?
8. How has HIV treatment influenced safe sex practices?

**Thank You**

**Appendix 5.1: Kaburi (Grave) By Vincent Senior**

| **Kiswahili** | **English translation** |
|---|---|
| Kaburi | Grave |
| *Kaburi ni tajiri* | Grave is so wealthy |
| *Kaburi ni mnyang'anyi X4* | Grave is a robber x4 |
| *Tangu mwanzo wa dunia* | Right from the beginning of the world |
| *Ulipochukua Abeli* | When you took Abel the first man |
| *Hadi leo haujashiba* | Till today you are never sastified |
| | |
| *Wabaya kwa wazuri* | The wicked and the righteous ones |
| *Waliotambulika* | Who were known |
| *Kaburi uliwachukua* | Grave didn't spare |
| *Dunia yaomboleza* | The world is mourning |
| *Kwa nini hautosheki?* | Why are you not sastified? |
| | |
| *Mandela* | Mandela |
| *John Paul II, Mother Teresa, Luther King* | John Paul II, Mother Teresa, Luther King |
| *Waliopigani haki za binadamu* | Those who fought for human rights |
| *Hata Yesu mwana wa Mungu* | Even Jesus the son of God |
| *Ulijaribu kuchukua* | you tried rob |
| *Lakini haukuweza* | but you were defeated |
| *Sababu hauna hauna nguvu* | Coz you have no powers over God's power |
| | |
| *Dunia yaomboleza* | The world is mourning |
| *Wasanii wa muziki waliotutumbuiza* | The music artists |
| *Kwa midundo motomoto* | who entertained with hit songs |
| *Kaburi uliwachukua ,* | Grave you took them |
| *Watu kama-* | People like |
| *Luther Vandrose, Sura Mbaya* | *Luther Vandrose, Sura Mbaya* |
| *Pepe kale,Lucky Dube wa Reggae* | *Pepe kale, Lucky Dube of Reggae,* |

| | |
|---|---|
| *Michael jackson, Madilu system* | *Micheal Jackson , Madilu System* |
| *Walikufa JUU YAKO yako Kaburi* | They died because of you grave |
| Mashujaa wa dhamana wa Kenya, | Prominent heroes of Kenya |
| Kaburi ukatunyanganya | You took them |
| Mzee Kenyatta, Tom Mboya, Oginga, | Mzee Kenyatta, Tom Mboya, Oginga, |
| Wamalwa Kijana, Samuel Wanjiru | Wamalwa Kijana, Samuel Wanjiru, |
| Wangari Mathai, Saitoti, Ojode, Michuki | Wangari Mathai, Saitoti, Ojode, Michuki |
| Waliotikisa ulimwengu kwa mabaya | Those who shook the world by evil |
| Kaburi pia haukuwasaza | You did not fear them. you took them |
| Idi Amini, Sadam Husein, | Idi Amini,Sadam Husein, |
| Osama bin Laden | Osama bin Laden |
| Ghadaffi, Hitler, Musolini | Ghadaffi, Hitler, Musolini |

**Appendix 5.2: Papa Lolo By Mose Fan Fan**

Aah!

*Boni boni banganga babelela ndoki ee*

(Why is is it that the witchdoctors hail witchcraft)

*Butu eyindi mokolo ya bandoki bangalaka Nzambe ooh*

(when the night fall and becomes dark thats the day/time when the witches praise GOD)

*Ntongo etaini bakolola nzoto bapemi makambo eeh*

(at the sunrise they remove their Christianity cocoons to perform witch craft, it's amazing)

**Chorus**

*Aaaah, Naleli mama a na leli papa a X2*

(Am crying for my mama, am crying for my father)

*Papa lolo eeh, babwakiyo wapi ee? X2*

(Mr lolo eeh, where did they dump you?)

*Na mokili bandimaka moto te ooh*

(In this world people never accepts anyone)

*Osangalaka liaka tuka*

(never complain that you're getting a raw deal)

*Mokili leka balanda yo eeh*

(in this world mind your own business and do

what's best people will follow you later)

*Ebale ezanga mikuwa ee*

(remember that the river doesn't have a bone)

*Baboti yo kotina lingomba*

(know that you were born in the society for a reason)

*Bandoki batitiseli yo miso ee*

(the witch will be always watching you with keen eyes)

**Chorus**

*Nzambe akela mokili,*
(God created the world)
*Atiya mpema na mopepe*
(he created breathe and wind/air/ he created life in it)
*Apesa biso mpema toi mpema*
(he gave us the breathe that you breath today)
*Akela biso na Edeni*
(he created the garden of Eden for us)
*Nzoka atiya biso na bowumbo*
(whereas he caged us in slavery)
*Ntango nyioso I LOVE YOU EEH*
(all the time we have to beg for love
saying I LOVE YOU EEH)

*Na mokili bandimaka moto te ooh*
(In this world people never accepts anyone)
*Osangalaka liaka tuka*
(never complain that you're getting a raw deal)
*Mokili leka balanda yo eeh*
(in this world mind your own business and do
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