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Elderly care in Chile.

Policies for and experiences of family caregivers

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whom I cared for only briefly
and will always care about.

Résumé

Contexte

La population du Chili est en train de vieillir après avoir amélioré avec succès ses conditions de santé et aussi en raison des progrès scientifiques et technologiques et des facteurs culturels, sociaux, politiques et économiques. Ces tendances ont contribué à la baisse des taux de mortalité, à l'augmentation consécutive de l’espérance de vie et à une réduction des taux de fécondité (SENAMA, 2013). En même temps, le nombre potentiel d’aidants familiaux de personnes âgées est en train de diminuer, en raison de l’augmentation de la participation féminine à la forcé de travail, des familles de plus en plus petites, d’un accès limité au marché des services de *care* et d’un soutien limité de la part du gouvernement et de la communauté. Le Chili reste un régime familialiste, ce qui signifie que la responsabilité de fournir l’aide sociale réside principalement à l’intérieur de chaque famille.

Pourtant, malgré son urgence, la prise en charge des personnes âgées reste toujours un sujet presque invisible pour les politiques publiques et la recherche au Chili. Pendant que dans les pays développés, le *care* aux personnes âgées devient une affaire publique, à travers le transfert des fonctions de *care* d'une sphère purement privée (familiale) à une sphère publique, communautaire ou d’une offre médiatisée par le marché (Anttonen et Sipila 2005) ; peu a été fait en Amérique Latine où le *care* aux personnes âgées reste peu étudié et surtout une affaire privée (Matus-López et Rodríguez-Modrono 2014).

Les changements dans la structure d'âge de la population chilienne ont eu lieu dans près de trois décennies, montrant une transformation démographique plus rapide que celle des pays développés. Cette transition a également été atteinte avec des niveaux inférieurs de progrès dans les services, dans les politiques et dans le développement général (Provoste 2012), expliquant en partie le retard dans l'attention du *care* aux personnes âgées, ainsi que le délai dans le développement des politiques de *care*. Le gouvernement chilien a commencé à prêter attention à la question du *care* aux personnes âgées, mais trop lentement pour faire des progrès importants en temps de crise. Le *care* aux personnes âgées a été reconnu comme une thématique qui doit être incorporée dans l’agenda politique du gouvernement, un premier pas très important et nécessaire. Les efforts sont pourtant principalement posés sur la reconnaissance du problème plutôt que sur la création d’interventions systématiques pour soutenir la prise en charge de personnes âgées.

Cadre théorique

Le concept de *care* est relativement nouveau dans les sciences sociales et fait encore l'objet de nombreuses discussions. Il n'y a pas de traduction définitive en français, par exemple (Martin 2014), ni un accord sur sa traduction à l'espagnol (Carrasco, Borerías et Torns 2011). Tobío et al. (2010) notent que *care* peut être un concept analytique nouveau, mais qu'il se réfère à une réalité ancienne. Jusqu'à la fin du XXe siècle, le *care* était naturalisé; il n'était ni questionné ni discuté. Les théoriciens-nnes féministes l'ont amené au débat, ouvrant ainsi un champ fructueux et prometteur pour la recherche sociale (Acosta 2015). Traditionnellement, le *care* était supposé appartenir à la sphère privée, ce qui a entraîné sa dégradation. Son statut relativement inférieur s'est étendu aux occupations et professions associées et, surtout, au travail des femmes. C'est cette dégradation qui a motivée les féministes a mettre le *care* au centre du débat (Lewis 1992; Daly et Lewis 1998).

Pour Knijn and Kremer (1997), *care* veut dire donner une attention informelle ou professionnelle à des personnes qui ont besoin d'aide dans la vie quotidienne. C'est la livraison d'une attention quotidienne, sociale, psychologique, émotionnelle et physique aux personnes. Le *care* couvre différents niveaux: individuel, relationnel, communal et institutionnel. Le *care* a une dimension privée et une dimension publique ; il peut être motivé par le désir d'aider et par la responsabilité (Martin 2008).

Sous-jacent aux activitées de *care*, il existe un phénomène complexe. Comme chez d'autres formes de *care* (aux enfants, aux handicapés, aux handicapés mentaux), le *care* aux personnes âgées suppose un receveur du *care* et un aidant. C'est nécessairement un phénomène social. C'est une relation, mais une qui implique aussi la famille, l'État, le marché et la communauté. C'est du travail. Il comprend les émotions. C'est une responsabilité privée, mais aussi une responsabilité publique (Martin 2014). Même si c'est inhérent à la condition humaine, l'activité de *care* couvre un certain nombre de relations, d'acteurs et de paramètres institutionnels divers. Son étude peut concerner l'analyse familiale, mais aussi l'analyse du marché du travail et de l'assistance sociale fournie par l'État ; il met en avant des concepts et des pratiques liés au travail, à la citoyenneté, à l'inclusion et l'exclusion sociale, aux émotions et aux réseaux sociaux, parmi d'autres (Leira et Saraceno 2008).

Le *care* est donc une notion complexe. Cela veut dire s'occuper des besoins matériels d'une autre personne. Cela peut également signifier que l'aidant ressent une préoccupation particulière ou un dévouement envers cette autre personne. *Care* signifie se soucier d'un autre, ce qui fait référence à une affection speciale ou à une préoccupation de l'aidant pour le bénéficiaire du *care*. Cela signifie également s'occuper de personnes dépendantes, ce qui fait référence au fait que l'attention des besoins matériels d'une autre personne est un travail. À la base des deux dimensions du care, de la souciance pour un autre et de la prise en charge, est le fait que le *care* est relationnel (Le Bihan et Mallon 2017; Leira 1994).

Ces questions analytiques peuvent être abordées aux niveaux macro ou micro (Daly et Lewis 2000, Martin 2008, 2012). Au niveau macro, le *care* social est étudié à travers l'analyse de l'infrastructure associée au *care*, des institutions connexes, des politiques de *care* et de la répartition des provisions de *care* parmi les différents acteurs concernés (famille, État, marché et communauté). Au niveau micro, l'analyse du *care* social explore la répartition du *care* entre la famille et la communauté et se concentre sur ceux qui reçoient ou effectuent le *care*, sur la nature des relations impliquées, sur les conditions dans lesquelles le *care* est fourni et sur les émotions associées.

Questions de recherche

Cette étude répond donc aux questions relatives aux niveaux macro et micro du *care* : Quelles sont les caractéristiques du phénomène du *care* aux personnes âgées au Chili ? Qui assume la responsabilité sociale du *care* ? Y at-il une crise de *care* ? Quelle est sa nature ? Quel est le rôle du gouvernement dans le régime de *care* aux personnes âgées au Chili, comment cela a-t-il évolué et quels sont les défis auxquels il est confronté ? À l'intérieur des familles où le *care* est fourni, qui et dans quelles conditions et situations s'occupe du travail de prise en charge des personnes âgées ? Qu'est-ce qui détermine l'intensité de l'expérience du *care* ? Les réponses à ces questions peuvent aider ensuite à répondre une dernière question: Comment le rôle du gouvernement peut-il s'adapter aux expériences et aux exigences des aidants ?

Méthodologie

Pour répondre aux questions relatives au niveau macro, cette thèse utilise une approche de méthodes mixtes. Elle s'appuie sur des enquêtes representatives nationales, à grande échelle, pour charactériser le contexte social et démographique du *care* et sa distribution. Elle repose aussi sur une revue de la littérature et sur des entretiens avec des informateurs clés pour décrire l'histoire des politiques et la répartition sociale du *care*, afin de caractériser le Chili en tant que régime de *care*.

Pour étudier le niveau micro du *care* au Chili, cette thèse adopte une méthodologie qualitative exploratoire en profondeur. Elle s'appuie sur 42 cas d'aidants familiaux principaux (filles, belles-filles et fils) qui résident à Santiago, la capitale chilienne. L'instrument utilisé fut celui d'un entretien semi-guidée. Cette approche permet d'explorer un phénomène complexe, en le capturant tel qu'il est ressenti par les aidants. La plupart des cas a été identifié par des professionnels du secteur social et de la santé, appartenants à différentes municipalités. L'échantillon n'est pas conçu comme un échantillon représentatif d'aidants, mais s'appuie sur différents types d’aidants pour saisir la variabilité de leur expérience. Des notes prises sur le terrain et surtout des photographies m’ont aidé à me souvenir des expressions faciales des aidants et du contexte physique où l'entretien a eu lieu, qui coïncidait souvent avec le contexte physique de prise en charge des personnes âgées.

Principaux résultats

La première constatation de cette thèse est que le *care* régime chilien, malgré tous les efforts politiques qui visent à appuyer la prise en charge de personnes âgées, reste très concentré sur une approche *familialiste par défaut*. Cela veut dire que la responsabilité sociale associée à la dépendance des personnes âgées est prise en charge presque exclusivement par les familles. Et par les femmes en particulier, avec des implications importantes sur les inégalités sociales et de genre, parce que ces femmes ne sont pas payées pour leur travail, elles n’épargnent pas pour leurs retraites et seront probablement prises en charge par leurs propres filles, qui, à leur tour, n’auront elle pas non plus un travail payé, ni pourront épargner pour leurs propre pensions.

Oui, le gouvernement chilien a commencé à jouer un rôle plus actif en ce qui concerne le *care* aux personnes âgées. Les sites Web sont là et le sujet se trouve dans le discours politique. Il existe des initiatives mises en place. Il existe un Service National pour les Personnes Âgées, SENAMA, institution qui coordonne l’élaboration et l’exécution des politiques de *care* aux personnes âgées. Il y a trois ans, le Président a annoncé le Sous-système National de *Care* et de Soutien afin d’avancer vers une répartition plus équitable du *care* aux personnes âgées.

Mais une analyse de la couverture de ces politiques, des rapports d’informateurs clés et de l’expérience spécifique des aidants affaiblit l'argument selon lequel le Chili appuie ou évolue vers une répartition plus équitable du *care* aux personnes âgées. Le développement des politiques reste incomplet. L’État n'est pas un acteur important au moment de soutenir le *care* aux personnes âgées ou même d’avancer vers une redistribution sociale équitable de celui-ci. Les programmes disponibles fournissent un certain soutien aux familles dans des situations socio-économiques vulnérables, suivant le principe de subsidiarité de la politique publique chilienne. La couverture et la participation aux programmes dépendent de la volonté des municipalités de les mettre en place et la couverture est limitée à très peu de participants. L’État n’offre aucun soutien aux aidants qui ne sont pas pauvres, ni a ceux qui vivent dans des municipalités qui choisissent de ne pas offrir les services. Il existe des services offert par le marché, mais ils sont trop chers sauf pour les familles à revenu élevé. Pour la plupart des aidants, le régime de *care* est familialiste par défaut. Comme c’est le cas dans un tel régime, le *care* aux personnes âgées au Chili reste en grande partie comme responsabilité des membres féminins de la famille sous la forme d’arrangements informels et non rémunérés, avec un soutien limité ou inexistant de la part du gouvernement.

Une deuxième constation clé est que le Chili subit au présent une crise du *care*. Le *care* dans un pays comme le Chili, est socialement insoutenable s'il s'organise presque exclusivement autour des aidants familiaux féminins informels. En s'appuyant sur les familles pour supporter le risque social du *care* aux personnes âgées - et sur les femmes au sein des familles -, le familialisme par défaut du régime de *care* au Chili perpétue des inégalités socioéconomiques et de genre profonds. La population du Chili est en train de vieillir, signe bienvenue du développement. Mais aussi, en raison des familles devenant plus petites et des femmes entrant de plus en plus dans la force de travail, le nombre d'aidants potentiels diminue. Cela conduit à la vision générale d'une crise du *care*: une croissance de la demande de *care* et une diminution des aidants féminins familiaux disponibles. Mais, comme le montre cette étude, la crise de *care* se réfère plus généralement à la répartition inadéquate de la responsabilité du *care* aux personnes âgées. Il manque des politiques appropriées et une plus grande couverture des efforts de l'État. Il manque aussi la possibilité d'accéder aux services du marché et le développement communautaire pour partager le *care* aux personnes âgées.

Cette crise générale du *care* est due à l'invisibilité et au manque de reconnaissance des personnes âgées et des activités de *care* dont elles ont besoin. Comme ni les personnes âgées ni leurs *care* ne sont valorisés socialement, la prestation de *care* repose sur ceux qui ont la moindre capacité de choix ou de décision, renforçant ainsi les inégalités sociales.

Les personnes âgées sont considérées comme des citoyens de deuxième classe et les femmes sont vues comme ses aidants naturels. Comme le détecte cette étude, dans les rares cas où les hommes sont les principaux aidants, leur travail est élogé et reconnu. Les hommes, contrairement aux femmes aidantes, sont soutenus par leurs proches, leurs collègues, leurs employeurs et leurs voisins; ils sont valorisés en tant qu'aidants. Les femmes ne sont pas valorisées en tant qu'aidantes de personnes agées, pourtant elles représentent 86% des aidants dans le pays. Ni les femmes ni les hommes ne sont reconnus par le gouvernement pour leur travail de *care*.

Ceci conduit à une troisième conclusion clé de cette étude: l'organisation sociale actuelle du *care* aux personnes âgées au Chili, perpétue les inégalités socioéconomiques et de genre. Ce sont surtout les femmes qui s'occupent du care, et, si les hommes sont impliqués, ils n'accomplissent pas les mêmes tâches. Les hommes contribuent au travail physique et au financement, mais sont absents de toute tâche plus intime. Les hommes reçoivent le soutien de ses frères et sœurs et de la communauté, les femmes, rarement.

Le *care* renforce également les inégalités socioéconomiques. La majorité n'est pas en mesure de payer pour un aidant externe et dépend exclusivement de la famille. L'aidant familial ne reçoit pas de salaire et n'épargne rien pour sa pension, risquant ainsi de vieillir dans la pauvreté. Et, à l’avenir, il-elle va dépendre d'un autre membre de la famille pour son propre *care*, l’empêchant à son tour de recevoir un payement pour son travail, perpétuant ainsi la vulnérabilité de la famille de génération en génération.

Ces constatations me permettent de conclure, comme d’autres auteurs l’ont fait, que, dans des régimes de *familisme non soutenu* ou de *familialisme par défaut*, comme ceux qui existe au Chili, la forte solidarité et protection offerte par les proches est le résultat de l'absence de soutien de la part du gouvernement. Ce n’est pas une caractéristique culturelle particulière des familles à revenu limité. La solidarité familiale n’est pas un moyen pour réduire les inégalités, mais à court et à long terme, c’est un facteur qui les augmente.

Une cinquième constatation est que cette crise de *care* se fait sentir tous les jours. Au cœur de la crise, du manque de soutien et de reconnaissance, se trouve une faible valoration de l’activité de *care*.

Le *care* est une activité qui existe uniquement dans la sphère privée et qui est rarement considérée comme un travail. Elle n’est reconnu ni par l’État, ni par les réseaux communautaires ou sociaux. Pour la plupart des aidants, leur travail n’est point reconnu.

Ce manque de soutien et de reconnaissance ajoute de la pression sur la vie quotidienne des aidants.

Une sixième conclusion est que la prise en charge d’un proche âgé est une expérience émotionnelle complexe, qui varie d’un aidant à l’autre. Tous les aidants partagent deux faits fondamentaux: ils travaillent dur pour fournir le *care* et ils expriment tous des émotions vives en parlant de leur expérience. Certains se sentent heureux et chanceux de pouvoir s’occuper de leurs parents, d’autres trouvent la situation injuste et voudraient que tout soit différent, mais n’ont pas de choix. Tous, soit qu’ils consacrent de longues heures ou juste quelques heures par jour au *care*, soit qu’ils partagent certaines tâches ou qu’ils fassent tous par eux-mêmes, soit qu’ils cohabitent avec la personne âgée ou pas, soit qu'ils soient un enfant unique ou qu’ils appartiennent à une grande fratrie, soit qu’ils disent aimer leur parent âgé ou pas, tous montrent des émotions vives lorsqu'ils parlent de leur expérience. Pour chaque aidant, l’intensité de leur expérience est en partie déterminée par les tâches spécifiques qu’ils accomplissent et le temps qu’ils consacrent au *care*, et est largement façonnée par leur histoire personnelle, leurs relations avec les personnes âgées et les autres membres de la famille, et selon la façon dont il ils perçoivent leur rôle d’aidants et les attentes idéales qu’ils ont par rapport au *care*.

L'expérience de *care* ne peut pas être comprise uniquement par rapport aux tâches et aux heures consacrées aux *care* direct, ni par les difficultés du contexte dans lequel le *care* a lieu. Pour comprendre vraiment l'intensité du *care*, il faut considérer la dimension émotionnelle de la vie quotidienne des aidants, et la façon dont elle ajoutera ou pas de l'intensité à l'expérience. L'intensité de l'expérience de *care* est alors le résultat d'une combinaison de facteurs objectifs, de contextes divers et de perspectives subjectives accordées par la dimension émotionnelle du *care*.

Une septième découverte est de genre méthodologique. Compte tenu de la complexité de l'expérience de *care*, c'est l'approche méthodologique qualitative qui est la plus appropiée pour la comprendre. Toute approche qui vise à comprendre le *care* devrait considérer le concept de façon neutre en termes de valeur; il ne faudrait pas imposer la notion de *care* comme une expérience négative (comme un fardeau, par exemple), ni supposer que l'intensité de l'expérience n'est déterminée que par le temps passé à fournir les attentions. La considérér de manière négative ou la réduire à des indicateurs spécifiques quantifiables, conduit à un compte rendu biaisé des expériences des aidants et à une sous-estimation des conséquences sociales que le *care* entraîne pour eux. La méthodologie qualitative dans cette étude contextualise et comprend le phénomène tel qu'il est ressenti par les aidants dans leur environnement quotidien et façonné par les relations sociales et les émotions impliquées.

Conclusions et idées pour le développement des politiques publiques relatives au *care* aux personnes âgées

Cette étude fournit une compréhension exhaustive de ce qu'implique s'occuper d'un parent ou d'un beau-parent âgé au Chili. Les analyses de niveaux macro et micro du *care* aux personnes âgées, se complémentent pour aider à comprendre ce phénomène complexe, et offrent un point de vue avantageux pour suggérer un développement possible de politiques publiques. En effet, la caractérisation du régime chilien de *care* aux personnes âgées en tant que typologie et l'étude de la politique récente du gouvernement en matière de *care* aux personnes âgées, donnent une image très limitée de ce que signifie vivre dans un tel régime pour ceux qui fournissent le care. Une analyse du niveau macro des politiques de *care* ne dit pas grande chose sur ce qu'est l'expérience quotidienne de l'aidant, sur l'intensité impliquée, sur la source de la pression qu'il subit, ou sur quels sont ses besoins et ses attentes. En même temps, l'analyse du niveau micro de l'expérience de *care* est mieux comprise dans son contexte plus général. Ensemble, ces éléments révèlent une réalité qui n'a pas été suffisamment étudiée par les sciences sociales et qui reste sous-développée et peu considérée par le secteur public.

Cette étude montre que le gouvernement chilien a fait d'importants efforts pour protéger la population la plus vulnérable depuis le retour à la démocratie dans les années 1990. Il a suivi, pour la plupart des iniciatives, une stratégie de subsidiarité, visant à corriger toute défaillance du marché. Des progès importants ont été atteints pour soutenir la population face aux risques concernant la santé et les finances et pour élargir l'accès à et la qualité de l'éducation. Ces efforts ont été particulièrement importants pour les personnes vivant dans la pauvreté. Des mesures ont également été prises pour accroître la portée de la protection à d'autres groupes vulnérables, tels que sont les jeunes enfants, les femmes et les personnes âgées. Pourtant, la protection sociale s'appuie fortement sur le domaine privé pour assurer la protection face aux risques, tel que celui d'être une personne âgée qui a besoin de *care*. L'État joue un rôle important parmi les groupes présentant la plus grande vulnérabilité et, à l'exception de quelques politiques ayant une couverture universelle (comme le système de santé publique de garanties explicites et la pension de base solidaire) est pratiquement absent pour le reste de la population.

En étudiant l'intensité de l'expérience de *care*, cette étude identifie les aspects de la politique qui nécessitent une considération urgente pour progresser vers une répartition plus équitable des responsabilités en matière de *care* aux personnes âgées et pour réduire l'intensité de l'expérience de prise en charge.

a) Augmenter la couverture des programmes existants de *care* aux personnes âgées.

L'analyse de niveau macro identifie un certain nombre de programmes disponibles pour appuyer le *care* aux personnes âgées. Au moins six programmes existent, le plupart d'entre eux parrainés par SENAMA. Ceci peut conduire à une conclusion incorrecte selon laquelle le soutien aux *care* aux personnes âgées au Chili serait adéquat. Le fait est, cependant, que la population qui peut vraiment accéder à ces programmes est minime par rapport à la celle qui en a besoin. Par exemple, seulement 0,3% de la population potentielle participe aux Centres de Jour pour personnes âgées et les listes d'attente sont tellement longues que lorsque des places deviennent disponibles, l'ancien éligible peut très bien être déjà décédé. Seule la population socioéconomiquement vulnérable est éligible. En conséquence, une grande partie de la population ayant besoin du programme reste hors son cadre ainsi que de tous les autres programmes ciblés selon un critère socioéconomique. Presque toutes les familles n'ont pas les moyens économiques de répondre aux besoins de *care* aux personnes âgées sous une autre forme que celle du *care* familial informel, non rémunéré, fourni par une fille ou belle-fille, aidante à temps plein.

La couverture est limitée davantage par la nature de prestation des services axée sur la municipalité. C'est à la municipalité de décider de mettre en place ou pas un programme parrainé par le SENAMA. Ainsi, selon la municipalité, les aidants vulnérables auront accès à différents programmes de soutien, ou à aucun programme du tout. Dans l'état actuel des choses, les municipalités peuvent choisir de ne mettre en place aucun programme de *care* aux personnes âgées. Plusieurs municipalités n'ont pas la capacité administrative de mettre en place des programmes, même s'ils ont suffisamment de personnes âgées dans leur population pour le justifier. Dans d’autres, le nombre de personnes âgées est jugé trop bas et il n’est pas possible pour différentes municipalités d’unir les efforts pour mettre en place des programmes ensemble.

La couverture est faible en grande partie en raison du financement insuffisant des programmes existants. Par exemple, le budget du programme *Cuidados Domiciliarios* (*Care* à Domicile) qui soutient les aidants et leur offre un répit de deux heures par semaine, représente moins de 10% du coût estimé d’un système de *care* formel à domicile (Matus-Lopez et Cid 2014). De même, et bien qu’il n’y ait aucune estimation du coût des garderies et des résidences de *care* aux personnes âgées, l’évidence internationale montre que ces programmes au Chili sont sous-financés (Genworth 2015 dans Matus-Lopez 2015).

Outre les contraintes financières, les aidants dans cette étude ont souligné la mauvaise qualité perçue et la difficulté d’accéder aux garderies et résidences de *care* pour personnes âgées, en tant que raison d’opter pour le *care* à temps plein et non rémunéré fourni par des membres de la famille. Le programme de *Care* à Domicile a été valorisé non pas pour le répit qu’il offre, mais pour la reconnaissance du travail des aidants qu’il transmet. L’augmentation du budget pour ce programme peut représenter une opportunité d’améliorer la qualité du *care* et d’offrir aux aidants un véritable répit.

b) Élargir les critères d'éligibilité aux programmes publics de *care* aux personnes âgées.

Tel qu’a été mentionné précédemment, l’éligibilité aux programmes actuels de soutien et de *care* aux personnes âgées est basée sur le niveau socioéconomique de la famille. Le niveau socioéconomique est mesuré par un instrument national, la Ficha de Protección Social (Fichier de Protection Sociale), qui sert également à évaluer l’éligibilité à d’autres programmes sociaux. Seules les familles ayant une personne âgée dépendante et jugés vulnérables par l'instrument, sont admissibles aux programmes de SENAMA.

L’éligibilité aux programmes de *care* aux personnes âgées ne tient pas compte de la situation des aidants ni de l’intensité de leur expérience. Baser l’éligibilité uniquement sur le niveau socioéconomique signifie ignorer le caractère émotionnel et relationnel de l’expérience de *care*. L’intensité de l’expérience de *care* devrait être considérée comme un facteur d’éligibilité et un indicateur d’intervention directe des programmes de *care* aux personnes âgées. Il ne suffit pas de se concentrer uniquement sur les aspects financiers pour évaluer l’éligibilité, ni de le faire uniquement sur le degré de dépendance des personnes âgées. L’étendue de tout soutien financier devrait être basée sur la situation financière de la famille, mais l’admissibilité pour pouvoir accéder au soutien et aux services ne devrait pas être limitée à elle seule.

Cette étude a montré que l’expérience des aidants est fortement associée à la relation qu’ils ont avec la personne âgée, leurs frères et sœurs et aux raisons pour lesquelles ils ont adopté le rôle.

Ces facteurs devraient être considérés au moment de déterminer l'admissibilité. De cette façon, les programmes pourraient identifier les aidants ayant besoin de support et favoriseraient leur bien-être.

Les résultats de cette étude montrent que les aidants appartenant à des familles de revenu moyen, reçoivent moins de soutien et sont attrapés dans une situation où ils doivent travailler pour maintenir leur famille, mais ne disposent pas de moyens pour externaliser une partie des tâches de *care*. Les aidants de familles à revenu moyen jonglent avec le travail et le *care*. Dans un contexte d'une absence absolue de politiques publiques pour concilier le travail rémunéré et les responsabilités en matière de *care* aux personnes âgées, les aidants à revenu moyen sont de loin les plus invisibles, ils ne sont pas dans la vue des politiques publiques et ils sont incapable d'accéder au soutien privé. De plus, les femmes à revenu moyen qui ne font pas partie du marché du travail, ne peuvent pas épargner pour leurs propres pensions, augmentant ainsi leurs possibilités de privation financière dans leur vieillesse.

c) Développer davantage de services pour atténuer l'intensité de l'expérience de *care* et réduire les inégalités liées aux *care.*

L'état émotionnel des aidants est d'une importance cruciale pour leur expérience quotidienne de *care*. Pourtant il n'est pas considéré dans les programmes et services actuels. Il ne devrait pas être laissé de côté au moment de concevoir des politiques pour atténuer l'intensité de l'expérience de *care*. Les politiques publiques concernant le *care* aux personnes âgées devraient tenir compte des besoins spécifiques des aidants, car l'expérience de *care* est complexe et diversifiée. Les aidants n'ont pas tous besoin du même type de soutien. Par exemple, pour certaines femmes, la difficulté à combiner une activité rémunérée avec le *care* aux personnes âgées est un problème majeur ; les politiques de conciliation ont pour elles une importance centrale. Pour d'autres, la situation idéale serait de recevoir une compensation monétaire associée à la fourniture de *care* aux personnes âgées ; un système de transfert conditionné serait la meilleur aide pour elles. Les programmes devraient offrir un soutien aux aidants qui souhaitent se consacrer aux *care*, mais aussi offrir la possibilité de dé-familiariser le *care* aux personnes âgées, en soutenant l'accès à des résidences de *care* de longue durée ou à des garderies. Cela peut s'avérer coûteux, dans ce cas, les programmes devraient favoriser un familialisme non marqué par le genre, en soutenant la participation des hommes au *care* aux personnes âgées.

Certains aidants adoptent ce rôle parce qu'ils n'ont pas de choix, mais ils préféreraient de pouvoir faire autre chose ou de combiner ce rôle avec d'autres. Les garderies pour personnes agées sont une alternative à la dé-familiarisation et offrent aux principaux aidants la possibilité de s'engager dans un travail rémunéré, s'ils le souhaitent. Ells peuvent être particulièrement bénéfiques pour les aidants à revenu moyen qui veulent combiner un emploi rémunéré avec leurs responsabilités de *care*. Les services de garde pendant le jour peuvent également offrir aux soignants à faible revenu, la possibilité d'entrer dans le marché du travail, car ils restent généralement hors du travail rémunéré en réponse à la supposition qu'ils ne pourront jamais accéder à un *care* de qualité pour leurs parents âgés. Fait important, les garderies respectent la nature relationnelle de l'expérience du *care*, car les personnes âgées restent en contact étroit avec leur famille. Au Chili, il n'y a que 14 centres en opération. Ils ne sont disponibles que dans une petite fraction des 345 communes du pays. Parmi ces 14 centres, un seul d'entre eux est dédié aux personnes âgées ayant une dépendance cognitive. Un cadre plus général de politiques de conciliation peut favoriser l'équilibre entre le travail associé au *care* et une activité rémunérée. Les difficultés actuelles pour combiner un emploi rémunéré et les responsabilités de *care* entraînent davantage de difficultés pour échapper à la pauvreté. Le manque de politiques de conciliation conduit à ce que les personnes qui travaillent et qui fournisse du *care* se compliquent énormément chaque fois que se présente une situation imprévue liée aux *care* (par exemple, une hospitalisation, un aidant externe qui ne peut pas venir au travail, etc.).

Il existe une importante dimension relative au genre dans la réussite d'un équilibre entre le *care* et le travail rémunéré. L'évidence dans cette étude, montre une plus grande probabilité de soutien informel offert aux aidants masculins. Les aidantes féminines ayant un emploi rémunéré, reçoivent moins d'aide que les hommes dans leurs lieux de travail, pour combiner les responsabilités en matière de *care* avec leur emploi. Les politiques gouvernementales devraient non seulement développer des politiques de conciliation, mais aussi adresser la dimension de genre associée.

Les politiques de conciliation ne devraient pas seulement se concentrer sur l'emploi formel, mais devraient également tenir compte des femmes travayeuses indépendantes ou dans des emplois informels.

Il est important que le gouvernement crée des opportunités pour que les personnes qui s'occupent des personnes âgées ou ceux qui ont été aidants dans le passé, puissent entrer dans le marché du travail. Le gouvernement chilien devrait faire un effort pour accroître la participation au travail des femmes (c'est l'une des plus basses parmi les pays d'Amérique Latine), indépendamment de leur statut familial (fille, mère, épouse). Offrir des alternatives de prise en charge peut favoriser cette participation. Elles comprennent équilibrer le rôle des hommes et des femmes concernant le *care*, redistribuer la responsabilité du *care* entre les membres de la famille, de sorte que ce ne soit pas seulement une des filles celle qui l'assume, offrir des options de qualité et abordables pour externaliser le *care*, travailler contre la discrimination laborale à l’égard des femmes, et créer des systèmes qui reconnaissent les capacités acquises dans le travail en tant que fournisseur de *care*.

Les programmes qui donnent des informations sur la façon de fournir le *care* peuvent être utiles aux aidants, mais il faut accorder une attention particulière au moment de la livraison. Cette recherche a révélé que ces initiatives étaient, contrairement aux attentes du programme, une source de pression pour les aidants quand le moment de la livraison n’était pas approprié. Les aidants qui ont ce rôle depuis longtemps reçoivent quelques fois des informations trop tard dans leur parcours, et ils pensent qu'il est déjà trop tard. Ils se sentent coupables si la façon dont ils fournissent le *care* est différente de ce qui est présenté par le programme.

d) Utiliser le potentiel des communautés pour répartir les responsabilités de soins de manière plus équitable.

En addition aux familles, à l’État et au marché, les communautés constituent un acteur important dans la répartition sociale du *care*. Les voisins, les communautés religieuses et les organisations locales peuvent et doivent jouer un rôle important dans le *care* aux personnes âgées. Au Chili, 96% de la population âgée avec un certain niveau de dépendance, ne reçoit aucun type de soutien de la part de ses communautés (SENAMA 2009b). Cela a également été évidencé par l’expérience des aidants considérés dans cette étude, le soutien de la communauté était généralement faible à l’exception de quelques cas. C’est un grand défi celui d’activer les réseaux communautaires et d’améliorer le rôle de la communauté dans le *care* aux personnes âgées au Chili. Comme l’a mentionné un informateur clé, pendant le gouvernement militaire, toutes les formes de soutien communautaire et de participation ont été éliminées. Le gouvernement a commencé à prendre des mesures à ce sujet avec le programme Chile Cuida (le Chili Soigne). Le programme forme et emploie des femmes sans emploi ou des femmes qui cherchent à augmenter leurs revenus. Il est important de noter que le programme adresse des femmes de la même communauté dans laquelle elles travailleront comme aidantes. Ces femmes visitent chaque personne âgée participant au programme, deux fois par semaine. Cependant, comme pour tous les autres programmes et politiques de *care* aux personnes âgées offerts par le gouvernement, la couverture est extrêmement faible. Actuellement, le programme Chile Cuida est opérationnel uniquement dans deux municipalités de Santiago, à l’exclusion non seulement d'autres municipalités de la capitale, mais aussi de toutes les autres régions du pays. Un programme de développement communautaire supplémentaire et plus complet concernant le *care* aux personnes âgées devrait être promu, un qui aille au-delà de quelques municipalités de la région métropolitaine.

Introduction

Antonia lives in the house she grew up in, a house in a middle-income neighbourhood at the end of an old gated street in downtown Santiago. Her house looks just like any other. Inside, however, there are things everywhere; she appears to have hoarding disorder, there barely is space to have a conversation. Antonia is 61 years old, she lives alone with her severely dependent mother. Antonia has no living siblings, her father has also passed away. She has no children.

Antonia is fully dedicated to her elderly mother's care. She stopped working as an independent dressmaker because she didn't have enough time to meet her mother's care needs. She pays for their living only with her and her mother's pension. She uses a variety of credit cards to buy medicines and basic goods. Antonia doesn't receive any help from other people; she lives in a municipality that offers no elderly care programmes to support her work.

Antonia's daily life is hard. She faces severe financial constraints. She hardly sees anyone other than her mother. But her experience as caregiver is primarily shaped by her feelings towards her role as a caregiver. Her experience, the feelings that shape her daily life, are more dependent on her personal history and her relationship with her overly protective mother than any specific set of tasks or financial or social constraints. Antonia hoards goods she finds on the streets or buys. She doesn't get rid of any. Her accumulation of things parallels the feelings she has accumulated over years of difficult relationship with her mother.

Antonia struggles, she feels overwhelmed. Care, for her, is unbearable. For Antonia, like all caregivers, the care experience has an emotional weight, shaped primarily by its relational nature. She gets angry and her anger stems from past unresolved issues with her mother. In retrospect, Antonia sees her mother as having been authoritarian and unavailable when she needed her the most. Antonia blames her mother for her loneliness: her mother was very apprehensive for any social contact she may have had and currently has with friends or her religious community. Antonia's mother's Alzheimer's disease doesn't help reconstruct their relationship.

Antonia regrets her life, she would like to run away. She cries a large part of the time she is awake. She watches television to disconnect. She keeps going as her mother's carer because she feels the moral obligation. Religion provides her the norms of how to behave as a daughter, which is to provide care. Religion also gives her the moral support to keep going.

This study reveals the daily experiences of family caregivers of elderly people and the policies in place to support elderly care in Chile. It highlights the complex nature of care work and explores the development of national policies to support elderly care.

Roughly 90% of the Chilean elderly are cared for in an informal, unpaid arrangement by a family member, like Antonia does. Care in Chile, as in most Latin American countries, remains largely the responsibility of female family members in informal, unpaid arrangements with little government support. The family is the main – and practically sole – actor responsible for elderly care in Chile. Family caregivers for the elderly in Chile come from all socioeconomic backgrounds, they have different ages and family structures. The great majority are women. They work hard, most of them for long hours. They give company to the elderly, change their diapers, make doctor appointments, cook for them, help them get dressed, etc. Many times they have to be available at all times in case something happens. Sometimes they do all care tasks by themselves. Some of them, the fewer, have the financial means to pay an external carer. Others, also few, receive adequate support from siblings or other people in their support network. Those living in a vulnerable socioeconomic situation receive some (little) support from the government for elderly care, if they are lucky enough to live in a municipality that implements the programmes offered by the State.

Caring for an elderly parent is a complex experience and is not as overwhelming for all carers like it is for Antonia. Some feel happy and fortunate to be able to care for their parents or parents-in-law. Others find the situation unfair and want everything to be different. All of them, whether they dedicate long hours or just a few hours a day, whether they share some tasks or do it all by themselves, whether they cohabit with the elderly or not, whether they are a single child or belong to a large phratry, whether they say they love their elderly relative or not, show vivid emotions when talking about their experience. For each and every caregiver, the intensity of their experience is partly determined by the specific tasks they carry out; it is largely shaped by their personal history, their relationships with the elderly and their other relatives, from how they perceive their caring role and their ideals expectations of care.

The experience of family caregivers takes place in the context of an emerging care crisis. Chile's population is aging after successfully improving the health conditions of its population, and also as a result of scientific and technological advances, and the cultural, social, political and economic factors. These trends have contributed to the decline in mortality rates, the consecutive increase in life expectancy and a reduction in fertility rates (SENAMA, 2013). At the same time, the number of potential caregivers is decreasing, as a result of increased female labour force participation, smaller families, limited access to the market for care services and limited support from the government or the community. Chile remains a familialistic regime, meaning that the responsibility for social welfare lies mostly within family.

Yet, despite its urgency, elderly care has remained an almost invisible subject for public policy and research. While in developed countries elderly care is "going public" through the removal of the care functions from an entirely private (family) sphere to public-, community- or market-mediated provision (Anttonen and Sipila 2005); little has been done in Latin America where elderly care remains understudied and still remains a private issue (Matus-López and Rodríguez-Modrono 2014).

Moreover, as this study shows, the care crisis refers not only to the expected deficit of family (mostly daughter) caregivers, but to the inadequate share of the responsibility for elderly care. There is a lack of appropriate policies and coverage of State efforts, a lack of possibility to access market services for care and a lack of community development to participate in elderly care. The care crisis transmits and maintains social inequality. The care crisis is due to the invisibility and lack of recognition for the elderly and a lack of appreciation for elderly care activities. Elderly care is socially devalued, it is seldom considered as work and is poorly paid in the few cases when it is actually paid (Acosta 2015). As care is neither socially not publicly valued, care provision lies on those who have a smaller capacity of choice or decision, reinforcing inequalities (Orozco 2010).

Chile's changes in its age structure took place in almost three decades, a faster demographic transformation compared to most developed countries. This transition was also achieved at lower levels and progress in services, policies and development (Provoste 2012), partly explaining the lag in attention to elderly care and the lag in development for elderly care policies. The Chilean government has begun to pay attention to the issue of elderly care, but too slowly to make significant inroads on the crisis. Elderly care has been recognised as a matter that needs consideration in the government agenda, an important and necessary first step. Efforts amount mostly to recognition of the issue rather than systematic interventions to support care.

Organised almost exclusively around informal female family caregivers, and in the face of a looming care deficit and crisis, elderly care is socially unsustainable.

This thesis takes a step towards a more equal distribution of elderly care by unveiling the voices of the many people, many of whom are women, who dedicate their lives to providing care to their elderly parent or parent–in-law. This thesis also maps the public policy scenario where care takes place to identify the gaps and opportunities for public policy to promote a more active public role in elderly care. This study, then, first explores how the elderly care is distributed in Chile and the government's role in this responsibility. The study identifies the major steps taken, as well as the challenges that lie ahead for a stronger governments' role and a fairer distribution of elderly care. It delves onto the care experience in their specific social, demographic and policy context, to recognise that Chile remains a familialistic regime and that the responsibility for elderly care lies almost entirely on the family. The study then explores the experience of elderly family caregivers. It explores how specific tasks, potential context-related resources or constraints and emotions shape their experience.

Chile provides a good entry point to the study of both the experience of care and care policies in emerging economies as some argue the country is experiencing a care crisis and the government is only beginning to develop policies to face it with fewer resources than those available to developed countries when they faced a similar situation. A deep understanding of care in Chile also allows for a critical appraisal of the current policy direction in the country and offer policy suggestions that are aligned to the provision and experience of care.

The main objectives of this thesis are, then, to a) analyse the social organisation of elderly care in Chile; b) examine the government's role over time and the challenges in adopting a more active role in elderly care; c) understand the caring experience and its intensity by the part of family carers, and ultimately d) to orient elderly care policies in Chile given the findings of previous objectives. Finally, the study draws on the macro- and micro- approaches to study care to better understand the social distribution of care, what it means for caregivers and what can be done to improve or adapt different actors' roles to the caring experiences' intensities and expectations.

By achieving these objectives, this thesis contributes to a comprehensive understanding of the phenomenon of elderly care in Chile. The study of the analysis of the social distribution of care and the specific role of the government (macro-level analysis) adds to the knowledge of the Chilean care policy context, contributes to the reflexion on the challenges that the Government faces to take on a more active role, and adds to the discussion on the care regimes typologies in Latin America.

But characterising the Chilean elderly care regime in one typology does not explain what it means to live under such a regime for those who provide care. A care regime typology does not say much about what their day-to-day experience is like or how intense it is to provide care to an elderly family member. Therefore, this research brings to light the experience of elderly care (micro-level analysis), understanding how their experience is shaped and lived. Taken together, these elements reveal a reality that has remained understudied by the social sciences and undercovered by the public sector, informing policy development and government's role to better suit the needs of family (mostly women) elderly carers.

The thesis is also a contribution to the study of care by adopting a qualitative perspective. This method acknowledges the complexity of the phenomenon without reducing it to a negative experience (e.g. a burden), or to the provision of specific tasks in isolation of their context, relations and emotions. Approached negatively or reduced to specific quantifiable indicators leads to a biased account of caregivers' experiences, and to an underestimation of the social consequences care brings to caregivers. Quantitative analyses usually result in weaker efforts to support care or in inappropriate support options that ignore the specific benefits caregivers accrue from caring.

The thesis is structured in three parts. Part I develops the theoretical framework and the context for this research. It presents the approaches to define *care*, and the theories and perspectives used to study it, both from a macro and micro perspective, and presents the research questions (Chapter 1) and the methodology used to answer the research questions (Chapter 2). Part II contains the sociodemographic context of elderly care in Chile (Chapter 3) and the policy context of elderly care in Chile, its evolution and the main challenges the government faces to promote a fairer social distribution of care (Chapter 4). Part III unravels the experience and daily pressures of family carers of elderly parents and parents-in-law in need of care. It describes the caregiving activities and the diversity in the role of carers (Chapter 5), how the immediate context of the elderly care experience shapes the caring experience (Chapter 6), and the more subjective elements that shape the intensity of the care experience (Chapter 7). The general conclusions present the main findings and recommendations for further research and policymaking.

This thesis is an invitation to comprehensively understand elderly care. It invites to grasp the policies and statistics, but also the faces, voices and the emotions of the invisible daily experiences of a subject that will cross the life of every human being. It is an invitation to understand how care should be everyone's responsibility yet still relies almost exclusively on a primarily female and voiceless population.

Part One: Analytical framework, questions and methods

Chapter 1. Analytical framework and research questions

Based on a literature review, this chapter presents the theoretical framework and the context for this research. It presents the approaches to define *care*, and the theories and perspectives used to study it, both from a macro- and micro-level perspective. In the context of care, the macro-level perspective corresponds, broadly speaking, to how care is organised in a society among, for example, the State, the family, the market and the community. The micro-level perspective refers to the distribution of care among the family and the community, focusing on the experience, the nature of the care relations and the emotions involved as well as on the conditions under which care is provided.

This framework supports the main research questions and objectives for this study on the organisation of care (macro) and the experiences related to caring for the elderly (micro) in the specific context of a Latin American and emerging country, Chile.

The study of the distribution of care and the Chilean government's role will identify elderly care needs in the country and how the State has developed to meet these needs. The study of the caring experiences through the lens of a micro perspective, will allow to understand how intense it is to be the caregiver of an elderly relative. These elements will illustrate the elderly care situation in Chile from a comprehensive and joint macro and micro perspective. Results will illuminate future policy decisions to alleviate the care intensities and meet the country's elderly caring needs and the caregivers' demands.

This chapter begins by describing the meaning of *care* and the dimensions of the concept. It describes the concepts and theories to study care from a macro perspective, by developing the notion of *care regimes*, or the roles and responsibilities of different societal actors (the State, the family, the market and the community). The chapter then develops the motivation to study care from a micro perspective, particularly the intensity of the caring experiences of those who provide care.

A great part of the literature used in this framework, is specific to the European or North American contexts where much of the research on this topic has been carried out, reflecting the fact that research on care, and more specifically on *elderly care*, is not well developed in Latin American countries or other emerging economies. Chile is not the exception for this lack of research. As developed throughout the chapter, this study advances knowledge on elderly care in one Latin American country to contribute to the understanding of the phenomenon in emerging economies where this topic remains understudied.

1.1 Analytical framework

In “Moral Boundaries”, Joan Tronto (1993) points out that we, as humans, are completely dependent when we are born. We depend on others for our survival and our social integration. We care for ourselves and as we age, will depend on others at different periods of our lives due to sickness, disability or old age. Simply put, care encompasses the activities carried out to satisfy the physical and emotional needs of dependent individuals (adults and children) and the normative, economic and social frameworks within which these activities are assigned and carried out (Daly and Lewis 2000; Lewis 1998).

Underlying care activities is a complex phenomenon. Like other forms of care (care for children, the handicapped, the mentally disabled), care for the elderly involves a care receiver and a caregiver. It is necessarily social. It is a relationship, but one that also involves the family, the State, the market and the community. It is work. It encompasses emotions. It is a private responsibility, but also a public responsibility (Martin 2014). However inherent to the human condition, the activity of care covers a number of different relations, actors and institutional settings. Its study can pertain to family analysis, but also to labour market and welfare state analysis; it brings to the fore concepts and practices related to work, citizenship, social inclusion and exclusion, emotions, and social networks, among others (Leira and Saraceno 2008).

The concept of *care* is relatively new in the social sciences and is still the subject of many discussions. There is no ready translation in French, for example (Martin 2014), nor agreement on its Spanish translation (Carrasco, Borerías and Torns 2011). Tobío et al. (2010) note that care may be a new analytical concept, but it refers to an old reality. Until the late twentieth century, care was naturalised; it was not questioned or discussed. Feminist theorists brought it to the debate, opening a fruitful and promising field of social research (Acosta 2015). Traditionally, care was assumed to belong to the private sphere, which led to the downgrading of care. Care’s relative lower status extends to the related occupations and professions, and, importantly, to women’s work. It is this downgrading that motivated feminists to bring care to the debate (Lewis 1992; Daly and Lewis 1998).

For Knijn and Kremer (1997), care means giving informal or professional attention to persons who need help in everyday life. It is the provision of daily, social, psychological, emotional, and physical attention to people. Care covers various levels: individual, relational, communal and institutional. Care has both a private and a public dimension; care can be motivated by both desire and responsibility (Martin 2008).

Care is thus a complex notion. To care means caring for the material needs of another person, and caring may also mean that the caregiver feels special concern for or devotion to another person. Care means *caring about*, which refers to caregiver's special affection or concern for the recipient of care. It also means *caring for* dependent people, which refers to the fact that caring for the material needs of another person is work. At the foundation of the two dimensions of care, *caring about* and *caring for,* is the fact that care is relational (Le Bihan and Mallon 2017; Leira 1994).

Scholars in social sciences, particularly those from Anglophone traditions, refer to care as *social care*, emphasising how care brings to the fore the dichotomisation of societal life into public and private spheres. By referring to care as social care, it is considered as an activity and set of relations that lie at the intersection of State, market, community and family relations (Daly and Lewis 2000). Social care is a shared need and a shared responsibility that goes beyond of the private sphere and expands to its broader social context (Tronto 2005).[1]

Understood this way, social care embodies three dimensions and related analytical questions. The first dimension of social care is that *care is labour*, inviting comparisons between care and other forms of work, analysing the conditions in which care is carried out (e.g. formal/informal, paid/unpaid, working hours). A second dimension is that *care is an obligation and a responsibility,* inviting to examine the nature of the social relations in which care takes place, the norms, obligations and expectations involved. Analyses of the State's role in care provision and how it weakens or strengthens existing norms about care fall under this dimension (e.g. specific care-support policies). Finally, *care is an activity with emotional and financial costs and benefits*, which raises the question of how these costs and benefits are shared among individuals, families and societies, as well as how the costs and benefits of caring for others may be evaluated (Daly and Lewis 2000).

These analytical questions can be approached at the macro or micro levels (Daly and Lewis 2000, Martin 2008, 2012). At the macro level, social care is studied through the analysis of care infrastructure, related institutions, care policies and the distribution of care provision among different actors (family, the State, the market and the community). At the micro level, social care analysis explores the distribution of care among the family and the community and focuses on who receives or performs care, the nature of care relations, the conditions under which care is provided and the emotions involved.

The following sections of this thesis describe in more detail the macro and micro dimensions of care, providing the theoretical rationale of this thesis to focus on i) the organisation of care in

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[1] Social care is a broader concept than that of social care services. Social care does not include medical health care (Anttonen et al. 2003, Martin 2014).

Chile and the government's specific role in elderly care (macro-level analysis); and ii) the experience of informal unpaid family caregivers (micro-level analysis).

1.1.1 Care from a macro perspective: The study of *care regimes*

As mentioned above, social care is a relationship entailing the care receiver and the caregiver. It involves individuals, the family, the State, the market and the community, as each of these actors play (or could play) a role in providing care (Arriagada 2009). Attonen and Sipilä (2005) introduce the notion of *care regimes* to identify and classify the patterns that govern these actors' involvement in the organisation of care across different societies.[2] Such patterns enable linking processes like individualisation, universalisation or the increasing public delivery of previously family-delivered activities to different care regimes. The notion of care regime allows for tracking the evolution of the organisation of care in a particular country and how public policy developments impact the role of other actors in the provision of care.

The State's specific role provides a starting point from which to analyse social care (Daly and Lewis 2000). Different welfare regimes are associated to different care regimes depending on how care responsibilities are distributed (Sainsbury 1999). It is not surprising, then, that the concept of social care emerges as a critique to the original typologies and formulations of the welfare regime (e.g. Esping-Andersen 1990) and its oversight in considering care as a key dimension of welfare and downplaying the family and women's role in the provision of care and welfare more generally. Feminists led this theoretical development, after highlighting that it was women who assumed the family's role in the provision of care (Lewis 1992; Arts and Gelissen 2002).

Care regimes in Europe

Esping-Andersen (1990) led one of the most influential attempts to categorise welfare regimes.[3] Though he does not distinguish or analyse caring issues directly, the notion of care regimes can be traced back to this omission and the developments to overcome it.

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[2] Glenn (2000) defines the *social organisation of caring* as the systematic ways in which care for those who need it is allocated and how the responsibility for caring labour is assigned. Caring can be organised in a myriad of ways inside or out of the household. For example, care can be provided in the home by a family member, a friend, or a community volunteer without pay or by a servant or homecare worker for pay. It can be provided in more collective settings such as community day care centres by a combination of volunteers and paid staff or in an assisted-living facility or a nursing home by paid employees. Furthermore, the care may be arranged and overseen by the care receiver, the care receiver's family, a non-profit entity, a government agency, or a for-profit enterprise. Caregivers can be paid by care receivers or their relatives, by private insurance, or by government agencies. These arrangements are not mutually exclusive. All these forms can exist simultaneously, and they often do in contemporary societies.

[3] Welfare regimes could, but do not necessarily need to include welfare states. Understood as constellations of practices that reallocate resources, welfare regimes may or may not include well-developed public policy (Gough and Wood 2004). Consequently, the study of welfare regimes sheds light on the redistribution of resources, whether or not such redistribution is State-led (Martínez 2007).

Esping-Andersen (1990) distinguishes welfare regimes according to the distribution of social responsibilities between the State, the market and the family along: a) the impact of social policies on social stratification; b) the degree of de-commodification (the degree to which individuals, or families, can maintain a socially acceptable standard of living independent of market participation); and c) the role of the family and family obligations, the market and the State in welfare provision. Three regimes emerge, each with different goals, different sources of solidarity and different protection levels. The *liberal regime* relies heavily on the market and aims at covering the needs through market and family obligations. Benefits are means-tested assistance, with some modest universal transfers or modest social insurance plans (e.g. Australia and the United States). The *corporate-conservative regime* has a strong degree of familialism with a marginal role of the market and a subsidiary role of the State (e.g. Austria, France and Italy). Finally, the *social democrat regime* guarantees universal social rights through citizenship (e.g. Denmark, Finland, Norway and Sweden).

The Esping-Andersen typology, in its original formulation, did not classify Southern European countries like Greece and Spain. Although Italy is considered to belong to the corporate-conservative regime, the original typology is limited in that Greece, Spain and Portugal are not covered at all (Arts and Gelissen 2002). The typology was extended to a fourth model, the *Mediterranean* or *Southern regime*, accommodating Greece, Spain, Portugal and other countries (Ferrera 1996, Rhodes 1996). The Mediterranean or Southern countries have little State intervention, minimum social protection and high levels of clientelism.[4] Among others, the Southern welfare regime is characterised by the family playing the role of the central nexus of solidarity (Martin 2015) with significant gender implications (Ferrera 2000).

Perhaps the most important limitation of the original Esping-Andersen typology is the exclusion of a systematic discussion of the family's role in the provision of welfare and care (Arts and Gelissen 2002, Martin 2015). Feminist scholars (e.g. Antonnen and Sipilä 1996, Daly and Lewis 1999, Leitner 2003) argue, for example, that the original typology does not consider the family and women's role in the welfare regime sufficiently (Arts and Gelissen 2002).

Several reformulations of the original typology overcome the limited consideration to all relevant actors in the distribution of care. Daly and Lewis (1999) add a fourth dimension, *social care*, to the analysis of welfare states in Europe. Analysing social care means analysing the roles of public and private actors in the provision of goods and services, like it is in the context of

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[4] Clientelism may entail personal relations between a politician and an individual seeking a specific favour, it may also emerge as reciprocal relations between politicians, political parties or political elites and social groups or social categories that can vary in size and characteristics. Mass clientelism will typically take the form of more formalised relations and be realised through the enactment of laws that serve the particular needs of the members of the group (Gal 2010).

both State/family and State/market provision. Social care also means analysing provision along other dimensions, including formal and informal work, paid and unpaid work, and State support in care provision in the form of cash transfers or services.

Antonnen and Sipilä (1996) integrate social care services to reformulate the welfare state typology to better account for the family's and women's role in welfare and care distribution. The provision of social care services by the State, the market or the community can excuse families and women, at least in part, from their caring obligations ('exit out of the family') and reduce their dependence on the male breadwinner, defining different regime types. Antonnen and Sipilä identify three models for European countries depending on the extent and type of public support:

- *Mediterranean model / Family type*: The family has a legal duty to support relatives, there is a lack of public support, and public benefits are needs-based and means-tested (e.g. Greece, Italy, Spain).
- *Continental model / Mixed type*: The family is the primary caring unit, but persons with more serious health problems have a legal entitlement to public services. This entitlement is a right and based on a public insurance system (e.g. Germany) or public provision (e.g. Austria and France).
- *Scandinavian model / Public type*: The public sector has the primary responsibility for persons in need for care. Family help is considered as a complement to public services (e.g. Nordic countries and the Netherlands).

Leitner (2003) goes further and analyses welfare regimes specifically through the family's role in the provision of social care. She pays specific attention to how social policies that support care shape the family and women's role in care. Policies can enforce the dependence of people in need of care on their family (*familialistic policies*) or can remove care responsibilities from the family and reduce the extent to which the satisfaction of individual care needs depends on the individual's relation to the family (*de-familialistic policies*).

As women usually provide family care, supporting the caring functions of families, as is the case in familialistic policies, necessarily represents a gendered subject. Leitner (2003) thus distinguishes between *gendered* familialistic policies and *de-gendered* familialistic policies. The former assigns family care to women (or men) only, devalue family care in relation to employment and focus on heterosexual couples. But familialistic policies can also include incentives to ensure that care provision is shared on equal terms among male and female family members. This is the case of *de-gendered* familialistic policies, they validate family care and enable financial independence of the carer, provide choices to move between family care and employment, and provide comparable benefits to different family arrangements.

The resulting division of roles and responsibilities across societal actors and the consecutive care regimes, fosters different degrees of de-familialisation or familialism. Drawing on Leitner (2003) and the extent to which policies support familialism or de-familialism, Saraceno and Keck (2010) and Saraceno (2010) distinguish patterns in European countries along the continuum of familialism and de-familialism. To analyse how far or how close a country is to familialism or to a de-familialism care regime the authors examine how social policies and civil law regulate the family caring and financial responsibilities towards the very young and the elderly, paying attention to both (implicit and explicit) gender and intergenerational expectations within policies. They distinguish three different patterns along the familialism/de-familialism continuum:

1) *Familialism by default*, or unsupported familialism: there are neither publicly provided alternatives nor financial support for family care. It can be implicit or explicit as in the case of financial obligations within the generational chain and kinship networks prescribed by law.
2) *Supported familialism:* policies, usually through financial transfers, including taxation and paid leaves, support (specific) family members in keeping up their financial and caring responsibilities.
3) *De-familialisation*: there is a high level of services for the elderly and children and the individualization of social rights (e.g. with regard to minimum income provision, or entitlement to receiving care) reduces family responsibilities and dependencies.[5]

Saraceno and Keck (2010) and Saraceno (2010) found substantial variation not only across European countries, but also when comparing childcare and elderly care within the same country. Very few countries show a similar approach in elderly care and childcare obligations. Childcare and elderly care has a different legal and social status and the different policy instruments belong to different policy settings and depend on different institutional actors.[6] The only group of countries with a similar regime in both elderly and childcare are Southern European countries (e.g. Italy, Greece and Spain), as well as Poland and Bulgaria. Portugal is an

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[5] De-familialisation is not in contrast with family and intergenerational feelings of responsibility and solidariry (e.g. Künemund 2008; Keck 2008) and de-familisation, particularly in the case of children, is never total. Furthermore, the extent of acceptable de-familisation in the case of children and of elderly may differ (Saraceno and Keck 2008).

[6] Saraceno and Keck (2008) consider three dimensions to identify countries in the familialism/de-familialism continuum in the context of elderly care policies. They identify whom and under what conditions are entitled to benefits and what is left to his/her own and family resources. The dimensions are: 1) whether (non-health) support is income-tested or universal, 2) the dependency above which one is entitled to receive support and 3) how much of the individual need is covered. To distinguish between de-familisation via publicly provided services, de-familisation via market services supported by public money and supported familialism, Saraceno and Keck consider two other dimensions: 4) whether support is offered in kind or as cash transfer, or a combination of the two and, in case it is offered as a cash transfer, 5) whether there are specific rules on how it should be spent.

outlier in this group because of the high degree of unsupported familialism that characterises childcare contrasts the well-developed levels of de-familialisation for elderly care. This characteristic situates Portugal also as an outlier among all countries since elderly care policies are usually less developed than childcare.

The closer a country is to familialism by default, the higher the possibility that social inequalities have a negative impact on the quality and the quantity of care received and on the resources and options available to family caregivers. Inequalities in access to public and market services are generally compensated with an increased recourse to family support. Family compensation may reduce inequalities among elderly in need of care, but increases inequalities between family carers. The higher the amount of care left to families, the greater the role that socioeconomic and gender differences play in the ability to substitute one's own care. Given the gender-biased obligation to care, familialism by default, in turn, affects both gender and socioeconomic inequality (Saraceno 2010, Saraceno and Keck 2010).[7]

In the same line, Martin (2015) argues that "(large) family solidarity or protection to relatives, as those present in *unsupported familialism* schemes more often prevalent in *Southern European countries*, is the result of the absence of support in the long run, because without this support, families are *forced and required* to assume many caring responsibilities. They *have to do so* as there isn't any real alternative. This family nexus of solidarity also explains the relatively marginal role of social assistance and, of course, also the high level of poverty, as family solidarity is certainly not a way to reduce inequalities, but rather a factor which increases them" (Martin 2015:89).[8] Policy and culture are interdependent. A family-oriented care culture might limit the willingness to offer de-familialising care policies, reinforcing family-oriented care culture and practices (Nadini et al 2016, Pfau-Effinger 2005).

The strong focus on the family in providing care for the elderly has been under pressure in recent years, particularly in those countries closer to a familialistic care regime (Pommer et al 2007). The large and growing gap between demand and supply in caregiving has motivated authors to denounce a *care crisis* or *care deficit* (Ehrenreich and Hochschild 2004, Glenn 2010). The number of people needing care has risen faster than the number of those available to provide care. Nutritional and medical advances have lengthened average life spans so that, at least in advanced economies, the fastest-growing segments of the population are the oldest age

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[7] Likewise, the de-familialisation regime through services provided by the market could also be a source of inequalities. Family resources inevitably mediate recourse to market care services and their quality with implications for social and economic inequality. Market-based de-familialisation policies can lead to familialism by default for groups unable to reach the market (Saraceno and Keck 2010).

[8] Martin (2015) argues that the strong family solidarity present in the Southern European countries is not a cultural nexus of protection in the sense that people develop a peculiar sense of family and mutual solidarity based on legal obligations within the kinship. On the contrary, he argues that it is more appropriate to consider that family solidarity is the result of the political configuration in these countries.

groups. In addition, medical and pharmacological progress has extended life for people with chronic health problems and serious disabilities. In parallel, trends such as smaller families, geographic mobility, and high rates of employment among women have contributed to shrinking the pool of those who have traditionally provided informal care (Glenn 2010).

European countries are all facing the dilemma of a higher demand for elderly care, a decline of potential family support for the dependent elderly, and the prevailing principle of cost containment. As a result, most of them have adopted policies to expand the provision of elderly care over the past 15 years even through a period of economic downturn. As Leitner (2003:3) notes, "especially in times with tight social budgets, it seems to be a reasonable strategy for welfare states to strengthen the family in its caring roles." Most of these countries have recognised that dependency is a social risk against which citizens have a right to public protection. Across Europe, for example, there is increasing attention to policy issues concerning elderly care and the challenge of how to best tackle the growth in the number of elderly people (European Commission 2011; Walker and Foster 2013). From this starting point, countries have extended coverage of social protection in terms of both access to care and the intensity of the care provided. The measures European countries have taken regarding elderly care share the following characteristics: a) a tendency to combine monetary transfers and in-kind services, b) the establishment of a new social-care market based on competition, c) the empowerment of users through their increased purchasing power, and d) the introduction of funding measures intended to foster care-giving through family networks (Pavolini and Ranci 2008). The public policies around care, can be interpreted as entailing the satisfaction of (one of) three types of needs: a need for services, for time and for cash, and there could be different types of provision of care: home-based and residential care, care leave, working adjustments and cash for care schemes, among others (Daly 2002).

The degree of familialism varies over time as the family regains its role as a core welfare institution during times of economic downturn (Casanova et al 2016). Also, among countries with developed formal care provision, the current elderly care debate has been focused on the preference granted to home care (as opposed to residential care), and the analysis of how to best integrate family care in a holistic care approach (Eurocares 2007). The policy trend in European countries, and particularly in Southern European countries with familialistic regimes such as Italy and Spain, is to improve the support and the integration of the informal actors into the overall care system (Schulmann & Leichsenring 2014).

Care regimes in Latin America

The understanding of care regimes in Latin America lags compared to the characterisation of care regimes in Europe. The policy experiences and the abundance of studies in European countries have allowed for detailed comparisons between care models and a rich discussion on policy lessons. A search for the subject of social care policies for the elderlies in the main electronic databases shows around 10,000 peer-reviewed articles, of which approximately 2,000 are from the past five years. A similar search limited to Latin America yields fewer than a dozen results (Matus-Lopez and Cid 2015).

The lack of knowledge of the reality of care in Latin America and the developing world is disproportionate to the size of its elderly population (Lloyd-Sherlock 2014). In 20 years, the South American elderly population will be larger than that of Europe, but little is known about the elderly in South America. The region is not prepared for this demographic change (Cotlear 2011) and, when the change arrives, countries will not have the resources that developed countries had when they had to adjust, rendering the evidence from the developed world less applicable to the Latin American context (Palloni et al 2006). Some have suggested a care crisis due to the projected increase in demand for care and the reduced supply of caregivers. Regional organisations highlight the unsustainability of relying on an unsupported family care regime. Support or alternatives to families in caring responsibilities need to be developed (ECLAC 2013). Despite this, little or nothing is known about this neglected policy area in these countries (Mayston et al 2014; Lloyd-Sherlock 2014).

In advanced economies, the consideration of care as a social risk began in the early twentieth century with the first social welfare programmes that would set the foundation for the welfare state (Casado y López 2001). In emerging economies, as those in Latin America, by contrast, this process has had a different evolution.

Filgueira (1998) was one of the first to adapt Esping-Andersen's work to the Latin American context and concluded that none of the conditions that allowed the emergence of the European welfare regimes are present in Latin America, highlighting that the Esping-Andersen typology is unable to classify Latin American welfare regimes.[9]

Rudra (2005) classifies Latin American countries according to whether they rely on public policies that predominantly promote access to the market (*productivist* regimes) or whether they predominantly protect people from the market (*protectionist* regimes). Martinez (2008) notes that all Latin American countries are, to some extent, *informal*, in that a large proportion of the population cannot reasonably expect to cope with social risks by accessing services from the State or by paying for services available in the market. In general, and in spite of differences in coverage and public policy, welfare provision in Latin America relies heavily on family

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[9] Filgueira (1998) focuses not only on the amount that countries invest in people's welfare but also on the criteria with which the investments are made. He focuses on how the allocation of resources is decided and implemented and focuses on the coverage of social protection across the population (not only on the degree of de-commodification).

relationships and the provision of care lies most frequently on female unpaid labour than on public policy.

From the perspective of care and still in the early twenty-first century, the policy discussion was still on whether care should be delivered by the family or the State (Guzmán and Huenchuán 2005). In Latin America, there is no consensus on whether care should be provided by the family, the market or the State, in spite of the empirical evidence highlighting how demographic change has caused problems in the provision of basic social goods (CEPAL and CELADE 2003).

Latin American countries are all *familialistic* regimes as families take over most welfare functions (Sunkel 2006). The familialistic regime has a relatively low capacity to absorb and adequately remunerate its workforce and, at the same time, social protection and human capital formation are minimally or intermediately de-commodified. In general, the Latin American familialistic regime and any resulting public policy do not free families and women of elderly caring responsibilities. The State in most of Latin American countries has also been practically absent in developing policies to de-familiarise and or to support families in caring responsibilities, especially in elderly care. Some countries, however, have recently begun to develop elderly care policies to alleviate families on this responsibility and to develop support for families with childcare (either giving allowance for maternal leave or offering formal childcare services). [10]

Policy measures related to care usually support families as welfare providers, as the family's role in social protection lies also in reaching out to garner the resources or services necessary for protection. The same happens in Southern European countries, which, in the context of European countries, have been labelled as primarily familialistic welfare regimes. In Southern European countries, women represent the link between the family and the State, as they deal with modern public institutions (e.g. hospitals, schools, public administration, etc) and family needs (Andreotti et al. 2001).[11]

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[10] See for example the care of Uruguay, the Latin American country with the highest proportion of elderly population and with a National System of Care that is already in place. Uruguay stands out in contrast to other Latin American countries. It is one of the smallest in population size, is well advanced in the demographic transition towards an aging population, is the richest, and is one of the most egalitarian. They have developed a National System of Care which includes elderly care services (as well as childcare and services for disabled people) with a focus on informal carers. Services are usually provided through a cash-for-care system for home-based services. Future developments of the system will expand provision in day care centres and residential and nursing homes (Matus-Lopez and Cid 2014).

[11] Although considered familialistic regimes, Southern European countries have made important advances in the recent past. There have been improvement in social benefits, expansion of childcare and elderly care services to support families as well as the development of family policy measures that were almost inexistent a few years ago (e.g. parental leaves, promotion of gender equality, etc.) (Martin 2015).

In this sense, Latin American regimes are transiting from an *implicit familialism* into an *explicit familialism*, one in which social policies motivate and need families for the provision of social protection (Acosta 2013). It is important, however, to note the distinction between the elderly and childcare policy scenario. Although there is a slight move to supported familialism, it is not possible to affirm that care regimes as a whole are moving from *familialism by default* to *supported familialism*, because policies towards the elderly care are by far less developed (Chapter 4 develops these ideas further for the specific case of Chile). When it comes to elderly care, the Latin American care regime remains implicitly familialistic by default, with only a few exceptions, such as in the case of Uruguay (Orlando 2016).

Precariousness of public devices for social protection of care needs is still observed in Latin America (Huenchuán 2009). These failures respond, in many cases, to the ingrained notion that many social risks, as is the elderly dependency, are of a private nature and not subject of a collective solidarity. Consequently, care falls almost exclusively on the responsibility of the family and inside families, on women (Provoste 2012), adding to the social, economic and gender inequalities.

As in Europe, within Latin America, the higher the degree of familialism of a country, the higher their social inequalities and poverty levels (Martinez 2007).

CEPAL (2010) ranks countries in Latin America regarding their welfare gaps according to the scope of their social protection policies, their labour market features and characteristics of the family and demographic structures. Under this typology, there is a group of countries that have wider welfare gaps: they are characterised by reduced scope for public spending and greater informality in the labour market, which coincides with a higher youth population and the highest percentage of households living under poverty (e.g. Bolivia, Ecuador and El Salvador, among others). At the other extreme are countries with narrower welfare gaps, which match with an aging population and greater formality in their labour markets (e.g. Chile, Costa Rica and Uruguay, among others). Another group of countries are somewhere in between these two extremes (e.g. Colombia and Mexico). Following this typology, policies for countries with narrower welfare gap policies should address in a short-term period care related policies for the aging population. For countries with the largest welfare gaps, policies should focus on young people and the unemployed, as well as putting a greater emphasis on childcare policies (CEPAL 2010).

The region's great cycles of development offer the best way to understand the relationship between social protection and the distribution of social care in Latin America (Provoste 2012). The economic crises the region has faced has led transformations of the States and the orientation of social policies. In recent decades, the trend is towards a greater role for the market, privatising welfare responsibility. Tasks that were once carried out by the State (e.g. in the 1950s) have been transferred to families and the market increasingly mediates provision. As a result, new needs, such as the care deficits described below, are not met by the provision of State services; markets are expected to solve any unmet demand. In this context, today, social protection and welfare are not always regarded as social rights (Aguirre 2007). Women's increasing participation in the labour market and the changes in the structure of the family have taken place without the State creating the conditions for the smooth unfolding of this process through public policies.

There is, however, progress in Latin American countries in moving towards offering social protection and welfare, particularly in terms of legislation, policies and programmes to take a more active role in providing care and ultimately improve the living conditions of the population. The greatest progress has been made by Costa Rica, especially with respect to childcare, and Uruguay where a National System of Care supports care for children up until three years old, for people with disabilities and for elderly people. Other countries like Chile and Ecuador have also made some progress, but with more piecemeal measures. Argentina has made some progress with their National Programme of Home-based Care Providers, which offers training to paid caregivers and home-based care services to poor families through the public health system. But the eligibility is restricted and waiting lists are long (Frayssinet 2015).

The progress is most salient in countries with an aging population and an increased capacity to provide social policies (e.g. Chile and Uruguay). In all countries, and as will be described in greater detail by studying the Chilean case in Chapter 4, however, a large share of the population, especially the elderly, lacks access to social security benefits, health services or basic services (Huenchuán 2009).

Despite the differences in the public provision of welfare across Latin American countries, governments generally assume that elderly care is primarily the responsibility of households. Public provision of goods and services tends to support households that cannot solve the caregiving needs of its members by themselves (Pautassi 2007) thus relying, implicitly and explicitly, on the family to provide care. Raising family care as a public issue and an object of public policy is still a pending task in Latin America. Even when care policies exist, they are seen as benefits for women, maintaining gender inequalities and resulting in a social and symbolic devaluation of their work (CEPAL 2010). Women have played a key role in the implementation of family care policy in the region. It has not always been explicit that women undertake these roles. Rather, policies have naturalised and instrumentalised women's role as society's main care providers. Social policies in the region count on women to stay at home available for the requirements of the State, so that they attend the family needs and responsibilities (Provoste 2012).

Following Leitner (2003), and taking into account the gendered distribution of care, Latin American regimes correspond to a *gendered familialism.* Policies assign family care to women, thus devaluing family care in relation to employment at the time they do not provide choices to move from family care to employment.

The distribution of care in Latin American societies is a reflection of the limited public offer for protection. It is also a reflection of the inequalities in accessing publicly supported social protection. Despite recent policy efforts, informal care remains the primary source of care provision and scarcely receives public support. There is a lack of alternatives to informal care and an insufficient offer of care services (private or public) to satisfy the demand for both current and future needs. Economic inequalities segment access to care services provided by the market and accentuate the stratification processes. Higher-income households can access services provided by the market. Lower-income households are to some extent supported by public policies. Middle-income households cannot access the market nor are they eligible for public services. Women remain the primary caregivers, maintaining gender inequalities (Del Valle 2011). Though gender discrimination is recognised to exist in public spaces and in the economic sphere, women's caregiving role is still assumed as natural (Provoste 2012). The recognition of women's unpaid work, and unpaid care work in particular, has not been part of the public discussion even considering its importance in welfare or its emergence in the international policy discourse through Strategic Development Goal number 5.4 (UN General Assembly 2014).[12]

The care deficit has been documented for developed countries and some Latin American countries are experiencing similar demographic care pressures (e.g. Argentina, Chile, Cuba and Uruguay). Life expectancy has risen; several Latin American countries match developed countries' life expectancy. Mortality rates have fallen as well; fertility rates throughout most of the region have also fallen so that they are now near, at, or even below the replacement rate in most countries (Jackson et al, 2009).

Chile is one of the most aged countries in Latin America, second only to Uruguay. In 2015, the percentage of elderly people reached 11%, compared with 8% for the region. Chile will become, by 2035, the country with the highest percentage of elderly population in Latin America, reaching 20% (UN 2015). Chile's demographic and epidemiological figures are in line with those that refer to a potential care deficit: Chile's population is aging and broader social changes and labour trends (e.g. women's progressive inclusion in the labour force) have contributed to a

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[12] Sustainable development goal number 5.4 seeks to recognize and value, by 2030, "unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate".

decreased in the availability of the traditional caregivers (women inside families) elucidating a potential care crisis.

Previous diagnoses point out that Latin America is not prepared for this change (Cotlear 2011), most countries do not have the resources developed countries had when first faced with care deficits (Palloni et al 2006). In Latin America, regional organisations have raised the issue of the impossibility of relying on family care given the demand pressures and supply limitations (ECLAC 2013). While in developed countries care is “going public” through the removal of the care functions from an entirely private sphere to public-, community- or market-mediated provision (Anttonen and Sipila 2005); little has been done in Latin America. Elderly care remains largely an invisible and private issue (Matus-López and Rodríguez-Modrono 2014).

In contrast to European countries, in Latin America the process whereby care functions shift from the private to the public sphere has been incomplete. Much of the care needs have never been met by the State and trends suggest that little is being done to face the imminent care crisis (Batthyány 2009). What is the situation in Chile? How far have public policies gone to meet the elderly care needs? What challenges remain? Having clarity on the policy context in which care takes place, attention can be given to the experience of those who provide care.

1.1.2 The micro dimension of care: The caring experience

The previous section showed how Latin American countries are closer to a familialistic regime than to de-familialism. They rely heavily on families, and more specifically on women, to provide elderly care. Care is usually provided by women in informal arrangements, with little or no government support. As important as the situation of care for the elderly is and will become in the near future and the magnitude and importance of informal caregiving, little is known in Latin America, and in Chile in particular, about the experience of the elderly family-caregivers, those that take on the largest share of the elderly care responsibility. There is a dearth of knowledge about the caregivers’ situation and how public policy can accommodate their needs and expectations.

A macro-level analysis of care can be complemented and enhanced by a micro perspective analysis. As Daly and Lewis (2000) note, a micro-level analysis of care may determine the distribution of care among the family and focus on who receives or performs care, the nature of care relations and the conditions under which care is provided. Caring responsibilities in a familialistic regime are associated with social and gender inequalities, but it is not clear how those situations are experienced and how people responsible for the elderly care provision feel about their caring role, how intense it is for them and what their expectations are. Although family carers are at the base of the Chilean care regime, their voice is silent, implying that this knowledge is minimal or simply ignored in policy.[13] But what does it mean, then, in practice for those who carry out the job? What is it like for a daughter or daughter-in-law to live in a familialistic care regime? How intense is their caring experience? What determines their experience?

Policy measures may be ineffective if they don't target the population needs and realities. This thesis, along with examining the policy context and the role of the government, will be help understand the experience of family carers of dependent elderly, so that future decisions can link to the specific reality of the people they target.

The following section delves into the theory and concepts of the caring experience and then analyses the different approaches to study the care experience. It provides the analytical framework to study care from a micro-level perspective.

The relational nature of care

As mentioned above, care is a complex phenomenon. It involves work and it involves emotions as it is embedded in a social relationship. Care as work is understood by *caring for* somebody; care as emotional work is understood by *caring about* someone (Tronto 1993). A distinguishing feature of care is that it is a social relationship (England 2005, Glenn 2000, Leira 1994, Ungerson 2005) and that it has an emotional component (Hoschild 2003, Montaño y Calderón 2010). Twig (2010) emphasises the emotional element in care work as it is embedded in interpersonal relations, in the feelings (often complex and conflictual) that make up family life. Feminist scholars have also contributed to the discussion of care as a social relationship highlighting this double dimension of care as work and emotions (see, for example, Glucksmann 1995, Twigg 2000 and Ungerson 1983). England (2005) describes care as a personalised relationship in which services are provided to help the development of people's capacities. It necessarily involves a relationship and an affective bond between subjects, and which in turn is subject by the intervention, not always coordinated, of the State, the market and the family.

To care means looking over the material needs of another person, and caring may also mean that the carer feels special concern for another person. Care as love, affection, concern and a personal relationship with another being is *caring about*. Care as work is *caring for* (Leira 1994). Understood as an inherent duality of work and emotion, care is not a heavy load or a joyful activity per se. The experience of care and how intense it is for the caregiver is thus not

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[13] Even in European countries, where the macro-level study of care is extensive, support policies exist and the benefits of informal caregivers for a sustainable elderly care regime has been recognised, knowledge about the experience of informal caregivers is limited. Little is known, for example, about caregivers' needs and experiences or the effects of caring on caregivers' work and health (mental and physical) (Colombo et al 2011, Courtin et al, 2014).

only a function of the tasks carried out. The experience of care crucially depends on the relationship between the carer and care receiver, the conditions under which care is given and whose choice it is (Kremer 2007).

The relational nature of care is also emphasised in the work on the *ethics of care* offering a comprehensive and political definition of care. The ethics of care highlights the contextualised nature of care. Under the ethics of care, care is a fundamental aspect of human existence. According to this approach, individuals are not considered as autonomous and rational but as interdependent on each other and their environment. Care is "a set of activities that encompass everything we do to preserve, extend and repair 'our' world for us to live as well as possible. That world includes our bodies, our self and our environment, all of which we seek to interweave in a complex web of life" (Tronto 1993:103). The ethics of care also highlights the relational aspect of care. Tronto (2012) also recalls two essential characteristics of care: it is relational in that individuals share a vulnerability condition of being both in a position to provide and receive care; and is also contextualised in the sense that "there are no two people, two groups, two cultures or two nations who practice or meet in the same way the care needs" (Tronto 2012:35).

The following section will develop the different approaches to studying the experience of care, highlighting their limitations and contributions.

Approaches to the intensity of the care experience

The care experience, and particularly its intensity has been analysed mainly through two perspectives, none of which take full account of its complexity. The first, especially common in the medical literature, measures the intensity of care by the physical and psychological effects on those who provide care. The care intensity in this perspective is commonly conceptualised as a *burden* for caregivers. The second perspective, common among economists, determines the intensity of the care quantitatively, by adding the number of hours of direct care provided to the dependent person by one or more caregivers. Neither perspective considers the relational and emotional context of the caring experience when assessing its intensity. Neither recognises that caring is more than just a set of tasks and responsibilities with negative consequences.

Research on the intensity of care rendered by informal caregivers of elderly people began in the 1970s. It has commonly been approached from a quantitative perspective, frequently using the concept of *burden of care.* Under this perspective, intensity of care refers to the *weight* or the *load* associated to caring for someone else. Care as burden is seen as a responsibility that is often the result of a moral, social, legal or economic imposition (García 2010). In its origin, the concept of burden of care emerged as a unifying notion shared by different groups of elderly caregivers (Kahana and Young 1990), to refer to the set of negative consequences that caring for a dependent person has for the caregiver (Bover 2004).

The burden of care perspective focuses on the physical and physiological effects of caring on caregivers' health status. It seeks to understand the caregiving experience, usually drawing on quantitative scales for depression, anxiety, apathy, fatigue or health. This research strand is based on the general model of stress, and tries to identify the risk factors and coping mechanisms that reduce the burden of care. It assumes that a caregiver who gives up caring implies a cost to society. Research on the burden of care brought the issue of care to the fore, contributing to the recognition of carers' work. It informed the development of public policies to support family caregivers by understanding care – and caregiving – as a public issue (García 2010). Today, researchers often distinguish between subjective and objective burden, and have proposed different instruments for measuring each.[14] Dwyer et al. (1994) define the concept similarly, as a disruption in daily routines, social relationships and other activities, as a result of care. The interruption or disruption posed by caring in everyday life lies at the centre of both objective and subjective burden of care.

In economic research, the intensity of care is measured by the number of hours dedicated to direct care for the elderly person. The objective, then, is to measure the time spent with the person in need of care, the specific tasks done related to care and the impact of time invested in labour market outcomes or its monetary value. Carmichael and Charles (1998, 2003) exemplify this perspective (and its limits). They studied the relationship between the caregiving activity and labour market participation. In a first study (1998), they measure how the hours invested in care impacts the female labour force participation and wages. Informal care provision beyond 20 hours a week negatively impacts female labour participation and wages; care provision below 20 hours a week has no effect. They then extend this analysis to cover men and gender inequalities and a more comprehensive set of indicators reflecting the care experience beyond the hours spent in care activities (e.g. the status as primary and only caregiver, cohabitation and the perception of financial assistance or not by the elderly person in need of care) (Carmichael and Charles 2003). Similarly, Fontaine (2009) continues the economic tradition of measuring intensity as hours dedicated to care when finding that non-intensive caregivers (those who care for less than an hour a day) are less likely to drop out of the labour market. Interestingly, he acknowledges, but excludes, the relevance of other dimensions of the care experience such as non-face-to-face emotional support or the psychological implications of caregiving. Both

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[14] The objective burden of informal caregiving refers to the amount of time spent on caregiving, the caregiving tasks performed, and possible financial problems. The subjective burden of informal care refers to how the informal caregiver perceives the impact of burden related to caregiving (Montgomery et al 1985). The distinction between objective and subjective burden of care is a first step to explore care from the perspective of carer's experience. It is a first step in breaking with a negative, instrumental, quantifiable and standardised definition of the experience of care.

Carmichael and Charles and Fontaine highlight how quantifying intensity of care in terms of hours of activity fail to account for the complexity and context of the care experience.

Time-use studies quantify the time spent in different activities (including care activities).[15] They have been instrumental in rendering care more visible in Latin American countries. These studies began in the 1980s in Cuba (1983), Mexico (1996) and Nicaragua (1998). Today, there are at least 18 Latin American countries that have conducted national studies on care and time use (Aguirre and Ferrari 2014).[16] In Chile, for example, the National Institute of Statistics conducted a Time Use Experimental Survey in 2008. The survey measures time spent doing non-paid work and differentiates between domestic and care tasks for different groups of dependent family members, such as minors, elderlies, sick and disabled. The study differentiates between physical care, emotional support, education, company and mobility support. Like in other Latin American countries, time spent in care contributed to visualising the investment and gender inequalities involved in care. Survey findings suggest that in the Metropolitan Region in Chile, for example, women's time spent in caring tasks almost doubled that of men, and that unpaid work has a monetary equivalent of around a quarter of the Metropolitan Region's GDP (INE 2009).

Other studies on the intensity of care focus on care activities directly. The National Study of Dependency conducted in Chile in 2009, attempts to measure the intensity of the care experience of dependent elderly caregivers by assessing the burden of care. The study measured subjective burden of care with a standardised scale.[17] The study finds that caregivers who have not taken vacations, who carry out the caring work alone and work longer hours rendering care experience have a higher burden of care. This study complements previous estimates made in Chile by Albala et al (2007) on the effects of receiving a monetary compensation for care from the government on the subjective burden of care and caregivers' wellbeing. They find that caregivers receiving the monetary compensation report lower levels of subjective burden of

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[15] There are several possible methodologies for studying time use, including ethnography, recall questions in surveys and time diaries (Mattingly and Sayer 2006).

[16] Time-use surveys began to be implemented under different modalities mainly in developed countries in the last third of the twentieth century responding to the demand for social and sociological research caused by changes in the demographic structure, the expansion of leisure activities and the interest of the media for audience analysis. Also, feminists and international organisations played a key role in these demands as they questioned the exclusive use of the variables relating to paid work and income and highlighted the importance of measuring domestic and care work as a substantive contribution to economies. These studies were incorporated into the social measurements, assessing the time spent on paid work, in domestic work, caring tasks, education, culture and leisure. For social sciences and statistics this meant a break in the traditional way to measure work, expanding the vision of what was considered as work. It also meant the visualization of the time spent on care, often invisible until then (Aguirre and Ferrari 2014).

[17] Subjective burden of care was measured with the Zarit Burden Interview.

care.[18] These authors also assessed the intensity of the care experience as the time spent in providing care, time since their last vacation and the frequency of the vacations. Measured this way, women's care experiences are more intensive than men's (Albala et al 2007).

Although assessing the objective burden and the number of hours invested in informal care is useful and necessary, it does not indicate how the informal caregivers experience their caregiving tasks. Some informal caregivers performing the same tasks may enjoy caring for a loved one, whereas others may find it a difficult and heavy duty (Werner et al 2010). These quantifiable approaches have limitations highlighted by several scholars (Ayres 2000, Campéon et al 2013, Connell 2003, De la Cuesta 2009, Le Bihan and Mallon 2017).

Quantifying care through scales and questionnaire items imposes an unequivocally positive or negative feeling to a particular situation. In reality, a particular situation can be a resource for one population group but a constraint for another. Research on the burden of care puts the focus on the negative aspects of care ignoring any positive aspects that may coexist with the negative and not necessarily compensate or offset them. Understood as stress, burden explains only a small part of the variation in experience. The economic and burden of care research reduce care to specific set of tasks; they reduce care only to its work dimension (i.e. only as caring for), ignoring the emotional and relational components of care, which can be particularly relevant for informal family caregivers. Indeed, burden and the experience of care more generally is more related to the meaning of a particular task or events than to the objective features of those tasks, events or circumstances.

García (2010) notes how the failure to correctly account for the experience of care in quantitatively-based studies has led to ignoring the multiple costs and benefits associated to informal family caregiving. Reducing care to the provision of specific tasks in isolation of their context, relations and emotions leads to a biased account of caregivers' quality of life and how caregivers' situation affects the quality of care. It has underestimated the costs of family caring with respect to care provided by public or private bodies, resulting in weaker public policy efforts. It has also led to underestimating the social consequences care brings to caregivers, resulting in weaker efforts to support them. It has led to offering inappropriate support options; by ignoring the specific benefits caregivers accrue from caring and ignoring their specific situation and context.

A more comprehensive approach to the intensity of the elderly care experience, one that recognises the complexity and multi-dimensional of care is found among certain authors (see, for example, Campéon et al 2013, Le Bihan and Martin 2008 and Martin, Le Bihan and Knin 2013). They acknowledge that the care experience takes place in a broader social context, that it

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[18] Albala et al (2007) also used the Zarit Burden Interview to assess the burden of care.

is a social relation and that the emotional dimension is essential to understanding the experience of care. This approach favours a qualitative methodology to better grasp the complexity of the experience of care. It systematically treats care as tasks, but does not ignore that the experience of care is shaped by the fact that these tasks take place in a specific context and that these tasks are social relations that involve emotions. The following sections will provide a deeper understanding of care as a set of tasks, their context, its relations and the consecutive emotions.

Caring tasks

Care is work, one that is often hard and heavy and which mainly involves only women (Graham 1983, Kittay 1999, Pautassi 2008, Sevenhuijsen 1998). Reduced to specific activities, care is work. The study of the caring tasks is a first important step in visualising care and it is also necessary, but not sufficient, to comprehensively understand the care experience. Caring tasks are the most readily identified aspects of care (James 1992) and provide a good starting point in analysing the care experience.

At a basic, pragmatic level, the experience of family carers involves carrying out many, varied tasks (Pentland and McColl 1999, Rodríguez 2006). These tasks can be grouped according to whether they are instrumental (help provided in activities of daily living such as cooking, laundry, cleaning, etc.), personal assistance (such as dressing, toileting, getting in and out of bed, etc.), emotional support, surveillance or organisational tasks (Campéon et al 2013).

Gender matters in defining who performs which caring task, consistent with a gender-based division of labour (Finch and Groves 1983, Kittay 1999, Parker 1993, Saraceno and Keck 2010). For example, most activities of daily life and personal assistance are provided by women, whereas men are more likely to engage in care management, transportation, home repair and maintenance tasks, or in intermittent assistance with occasional tasks.

The visualisation of the time spent in caring tasks and quantifying its psychological and physiological consequences is an important step in the recognition of care as an issue at the societal level. However, these approaches do not provide a comprehensive understanding of the experiences of those rendering care. Though care is work, these approaches fail to account for the fact that care work encompasses emotions as well (Hochschild 2003, Le Bihan and Mallon 2017).[19] Carers, and especially family carers, do not only *care for* dependent individuals, they also *care about* them. The emotional dimension is a main element in how care is experienced (Garcia 2010, Le Bihan and Mallon 2013, 2017). The intensity of care includes the tasks and direct investment in caring activities as well as the ever-present worry caregivers may experience even when not carrying out a specific care task or providing direct care (Campéon et

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[19] The support of an elderly in need of care is not only a rarely recognised form of work, but work that takes place in a specific emotional context (Le Bihan and Mallo 2017).

al 2013). As Barnes (2012) puts it, humans are emotional beings who respond emotionally not only to their frailties, but also to those of people close to them. Tronto (2005) notes how caring implies an on-going responsibility and commitment that makes us spend energy toward the object of care. Consequently, care is relational, and since the object in question is a human being, caring involves an understanding of and a response to the other's needs and expectations, as well as the context of the particular relationship (Paulsen 2011).

Care work does not take place in isolation and given the relational nature of care, the care experience cannot be understood solely in terms of the set of tasks involved, the context where it takes place and the emotions involved should also be taken into account.

The care context and the experience of care

The experience of care needs to be understood in the context where it takes place. The context creates situations that can become resources that improve the experience of care or become constraints that make the experience of care more difficult. For Campéon and Le Bihan (2013), caring situations are associated to the carer (e.g. the economic conditions of carers, carers' advanced age, their multiple caring demands, etc.); to the elderly person (e.g. the level of dependency and the nature of the pathology); or to the organisational context (e.g. the informal support and the medical and social offer of services). To some extent, the macro level, the organisation of social care among different sectors and the availability and accessibility of care services and support shapes the context in which care takes place and the relations that emerge; care relations are culturally and politically shaped (Ungerson 1987).

From the perspective of the caring experience, specific situations and contexts, do not unequivocally become resources or constraints for the caring experience (Le Bihan, Martin and Knijn 2013). A high level of potential constraints does not necessarily translate into a negative care experience (Soullier 2012), though it can make individuals more vulnerable. It all depends on how things are experienced by caregivers (Campéon et al 2012). The activities involved in care, the time spend providing care and the context in which care takes place do not necessarily reflect the intensity of the care experience. This is in part the reason why most of the research that analyses the relationship between care context and specific situations (such as combining care work with a paid job, caring for a very severe dependent parent, cohabitation between the carer and the care receiver, etc.) with the intensity of the care experience usually yield vague and contradictory results.

For example, for a caregiver, the availability of a social support network can sometimes become a constraint or a resource. Counting on a social support network can be a resource for improving quality of life and wellbeing of the caregiver (WHO 2001). Generally, a larger support network is preferable to a smaller network (Williams and Dilworth-Anderson 2002). Though social support usually has a positive character, it does not always equate to greater wellbeing for the person with care needs or the carer. A wider social network can be a source of intrusion, bad advice and conflict, rather than a source of help (Lefley 1997). Larger families can entail conflicts related to the negotiation of care responsibilities among members, contributing to caregivers' negative care experiences (Davey and Szinovacz 2008). The simple availability of a social support network does not provide a comprehensive picture of how the context influences the care experience.

Similarly, studies that examine the relationship between holding multiple roles (e.g. caregiver who is simultaneously a spouse, employee and/or parent) and the family carer's intensity of the experience have show contradictory results. In principle, holding multiple caring roles could be considered a constraint because of the burden it poses on caregivers. Along this line, some studies find that holding multiple roles was problematic for caregiving (Stephens et al 1997) and linked to higher depression levels and lower wellbeing (Marks et al 2008). However, other studies find that holding multiple roles does not relate to negative outcomes in the care experience (Dautzenberg et al 1999, Li et al 1995, Raveis et al 2000). Though multiple caring demands can reduce the caregivers' time and increase the number of caring activities carried out, they can also be a source of respite from specific care experiences (Duxury et al 2009). In other words, complementing the analysis of the care experience with whether caregivers have other roles (or not) is necessary but is not enough to provide a comprehensive understanding of the intensity of the experience; other variables must be considered as well to better understand the intensity of the care experience.

An elderly person's characteristics, both personal and situational, provide another set of contextual factors that could become a constraint (or not) for carers' (Brubaker 1990, Campéon et al 2013). In general, the older elderly people are the more vulnerable they are to disability. The older elderly people are, the heavier the care needed and the greater the constraints their care can pose on the carer's life (Brody 2006).

Being the caregiver of a dependent parent living in an elderly institution might also be a resource for some carers (as they might have to spend less hours providing direct care and have more free time and respite) but it could also be a constraint (Brodaty and Donkin 2009). Relief and stress reduction may follow institutionalisation (Aneshensel et al 1995), but so can guilt, anger, depression, and financial problems (Tornatore and Grant 2002). The contextual fact of the elderly's residential status doesn't, by itself, help to fully understand the intensity of the care experience.

Along the same lines, cohabitation between the elderly in need of care and his or her caregiver is a constraint for some caregivers and a resource for others. Accordingly, research shows mixed results. Cohabitation is appreciated as carers are more available and do not have to over-adjust their routine to provide care (Call et al 1995), it allows for a more reciprocate relationship among mothers with dependency and their daughters (Dwyer et al 1994), and is linked to a lower prevalence of depressive emotions (Montoro 1999). However, cohabiting with the elderly in need of care could negatively interfere in the relationship between the carers and his/her family (Brody 2004, Walker et al 1995), can increases the perceived burden of care and lead to a lower satisfaction with care by those who receive it (Dwyer et al 1994). When a carer cohabits with the elderly in need of care, more time is dedicated to caring and a greater variety of care tasks are done (Bittman et al 2004, Fast et al 2004). The inability to escape caregiving responsibilities weighs on carers who live with their care receivers (Joel and Martin 1998).

Although it is important to situate the care experience in its objective context, it is not enough to understand the intensity with which it is felt. Mattingly and Sayer (2006) show how similar objectives constraints are experienced with different levels of pressure. They show, for example, that the time pressure experienced differed among men and women who distributed their time for leisure and home and care activities equally. Women with an equal amount of leisure time than men have higher probabilities of experiencing more time pressure than men. The feeling of pressure is shaped by gendered norms and social roles, and not necessarily by the objective time constraints. Martin, Le Bihan and Campéon (2013) study the daily pressures experienced by caregivers engaged in a paid activity while being main carers of an elderly. They find that daily pressures (difficulties that families face when juggling paid work and care responsibilities) vary not only depending on the level of constraints of different situations (such as working conditions, family configurations, geographical distance, etc.) but that they might be related to other more subjective variables, such as the perceptions of the quality of the relationship with the elderly and the rest of the family, the representation of one's role as a caregiver and as a worker, etc. They conclude that, although contextual factors are important to understand the daily pressures, it is necessary to go beyond and consider how they relate to subjective variables as well.

Little is known about the context of elderly care in Latin America and its relationship to the care experiences. In Chile, for example, the 2009 National Study of Dependency of the Elderly in Chile includes a specific module on the dependent elderly's main caregivers. The module measures several contextual and sociodemographic characteristic of the caregiver and the elderly in need of care, such as the age of caregivers, the dependency level of the elderly they care, the socioeconomic status and the residential arrangement. As described above, the study includes a measure of the caregivers' subjective burden of care.[20]

Comunidad Mujer, an NGO promoting women's rights in Chile, has touched upon women caregivers' situation in the context of identifying factors that hinder women's participation in the labour market (Comunidad Mujer 2012, 2014, 2016). Besides these relevant attempts to explore and describe the elderly care situation in Chile, little is known about the context of elderly care and how it affects the caregiving experience. If the context of care remains poorly studied in studies on the experience of care, the subjective variables are even less considered.

Given the relevance of contextual factors – but considering their limits – it is relevant to ask: What is the context in which elderly care takes place in Chile? What are the different situations elderly carers face? Are the differences in the contextual factors enough to understand the different caring experiences?

Emotions' weigh on the intensity of the care experience

The explicit attention to emotions to understand social phenomenon is relatively recent, beginning only in the late 1970s with development taking place in the 1980s. Arlie Hochschild pioneered this work by incorporating emotions as a key means to access any phenomenon or social situation; with the study of emotions, new social phenomenon and their precise nature come to light (Hochschild 1975, 1979, 1983, 1990). Arlie Hochschild, and also Theodore Kemper (1978), shows that emotions are not a biological absolute, but are conditioned by social norms. Kemper (1978, 1990) notes that most human emotions are nurtured and make sense in the context of our social relations. That is, the nature of emotions is conditioned by the nature of the social situation in which people feel. Emotions are the embodied expression, in each individual, of the rich range and forms of social relations. Kemper shows that emotions usually originate in and derive from social relations. The description, explanation and understanding of reality is incomplete, and therefore false, if the sentient actor in the human play of interaction is not incorporated (Bericat 2000).

Emotions are generally understood as individual, personal or subjective phenomena. For Fernández et al. (2014), emotions are an affective phenomena most often marked by body states, thoughts, situations and expressions more or less controllable. The sociology of emotions recognises the embodied dimension of emotional experiences, as well as the subjective dimension of perceptions, thoughts, or moral appreciations that may be at the origin. Sociology,

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[20] Although including measures on the caregiver is an important step to understanding their experience, it has received very little attention. In the study's 100-page report, for example, only one and a half page is dedicated to discussing the results of the caregivers' module (SENAMA 2009).

unlike psychology or neuroscience, insists on the social, cultural, political, historical dimensions of emotions.

While emotions are the subject of a renewed and recent interest in social research, their analysis in the realm of care is concerned more with specific situations and professional activities (Le Bihan and Mallon 2017). Social research on disease and health has drawn on emotions as an analytical perspective to understand the transformations of care and professional practices (Drulhe 2008). Sociologists have highlighted how emotions regulate the care relationship (e.g. in a health professional-patient relationship), concerning the neutralization of emotions by the part of professionals or the control of emotions by the part of patients (Castra and Cresson 2008). However, few analyses consider the forms and effects of emotions in the family context or, more specifically, among those who care for a relative (Le Bihan and Mallon 2017)

The previous sections showed that the care experience cannot be solely understood by considering only the tasks and amount of time involved or expanding the analysis to consider the contextual characteristics where this care takes place. The missing dimension in the understanding of care are emotions. Caregivers' intensity of the experience is influenced by emotional factors that go beyond the specific caring tasks and the context where it takes place. Emotions associated to individuals' care experience contribute to explaining why a set of situations – tasks and context – can become constraints or resources.

By including the emotional dimension of care in the analysis of the care experience, the specific tasks and the context of care become potential constraints that determine the intensity of an experience. Emotions help explain the common observation that the accumulation of potential resources or constraints is experienced differently by different caregivers. Under this notion, the context and specific tasks carried out, in relation to a carer's specific emotions create different potential levels of intensity of the caring experience for different caregivers. The intensity of the care experience will be determined by the context, the work and the emotions associated to care (Le Bihan and Mallon 2017).

Approached this way, the *intensity of the care experience* is value-neutral as opposed to *burden of care*, which is necessarily negative. An approach through the emotional dimension is necessarily subjective and is not limited to the care-related tasks or to the accumulation of resources and constraints of a particular context. As Campéon and Le Bihan (2013) point out, the intensity of the care experience depends on the way situations are lived by caregivers and care receivers. It also allows incorporating carers' norms (e.g. reasons for becoming caregivers) and expectations (e.g. ideals of care[21]) and their relationship of the care receiver and others

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[21] The notion of *care ideals* has been used to analyse the moral predicament caregivers face when deciding to care and in deciding between paid work and care, or balancing both. For example, when women make the decision to work, many face the following dilemmas: How can I make sure my elderly

closely involved in the care arrangement (e.g. spouses, other family members, community members and institutions).

Caregiving for an elderly relative is thus a mosaic of measurable variables (such as caring tasks, time spent in direct activities and specific contexts) but also of the distinct and complex interpersonal experiences the people involved go through (Gubrium 1991). Individuals construct their experiences by acting and interacting. Care practices also mobilise moral considerations about what is right or wrong, what should or should not be done. Individuals therefore act according to a series of "reasons". For some, care is an obligation, a social prescription. For others, it is a sacrifice based on a feeling of debt. Sometimes individuals become caregivers for pragmatic reasons – simply because they see no other choice. While in other cases, individuals feel they must care for their elderly relative because they feel dependent and weak, and because this relative holds a dominant position over them. The origins of the investment of carers in their role, the nature of the decision, obligations, motivation or reasons to become a carer of an elderly parent or parent-in-law in need of care has consequences in carers' emotions and in the way they experience their daily life (García 2010).

The diversity of these values and situations translates specific relationships between the constraints and trade-offs into emotions and, ultimately, into different intensities of the care experience. They motivate individuals' determinations and choices, and link them to a number of conditions: social, gender, family history and social trajectory, among others to understand the diversity of different groups' care experience (Martin 2008).

Emotions result, in part, from the relational nature of care

Most of the emotions towards care emerge from caring work's relational component. Relationships can make a very difficult caring situation to be experienced with positive feelings. Relationships that give rise to conflict can make that a comfortable care situation become one felt with strong pressure. The emotional dimension, analysed in a qualitative perspective, appears as a main element of the modulation of the intensity of care (Le Bihan and Mallon 2017).

Care work does not exist in a vacuum; it is embedded in intimate personal relationships, it is embedded in social relationships (Abel 1991). More broadly, the quality of people's lives depends on the quality of the social relations in which they live, and on how people treat one another (Sayer 2011). A positive relationship between the carer and both siblings and the elder

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parent is properly cared for? What is proper care? And can I find a solution for care that fits my ideals for care? These considerations are moral and emotional. For women, to work or care is a moral predicament. Their decision is based what they consider appropriate as defined by cultural values, gender, morality, economics and more (e.g. a logic of "appropriateness") (Kremer 2007)..

in need is important to the carer's experience. The relationships the caregiver maintains with his or her social environment are crucial to understand their emotions and the intensity of the care experience. Carer's emotions towards their situations cannot be interpreted without consideration of the relationships in which these situations are rooted. Care is commonly the product of an intensification of a pre-existing relation pattern (Walker and Pratt 1991) and the intensity of the care experience is rooted in a historical relationship with the elderly in need of care (Le Bihan and Mallon 2013). Exchanges in the family build the moral commitment to care in situations of dependency. Situating the historical relationship between family members allows a better understanding family carers' investment, their emotions and their daily experience (Campéon et al 2012).

The provision of care for an elderly parent or parent-in-law is situated in a relational history between the carer and the elderly. The provision of care by children is unique in that the nature of their relationship with a parent was, at one time, a period of dependence on the parent who, for much of the child's life, would have been viewed as an authority figure who provided nurturing and resources. Upon assuming the caregiving role, however, the adult child becomes the support provider as the parent becomes dependent on the child for assistance. This may result in a shift in the relationship and a reversal in roles, which highlights the importance of exploring the both current and past parent-to-child relationship (Bastaworous 2011).

Considering care from a relationship perspective, acknowledges that family members live interrelated lives, resulting in interdependent development and roles that people assume are constructed over time (Marks et al 2008). Understanding caring from this perspective implies that the pre-caregiving relationship may have important implications for how the caregiving relationship develops. For example, adult children who recall being rejected or poorly supported by their parents in childhood are less involved in their parents care in later life (Whitbeck et al 1994). Also, high-quality parent-child relationships in the past tend to be associated with more positive caregiving experiences (Bastawrous 2011).

The relationship the caregiver maintains with his or her siblings is also an important component of the care experience. The presence of brothers and sisters can be a resource for main carers but it could also be a source of pressure, depending on the relationship between the siblings. Because families are an important source of social and emotional support to their members, as well as a potential source of pressure, conflictive relationships among siblings can have damaging effects for family caregivers of an elderly (Scharlach et al 2006). Families disrupted by conflicts or other signs of family dysfunction provide less assistance to members in need of help (Lieberman and Fisher 2001) and less social and emotional support to those family members who have primary care responsibilities (Gaugler et al 2003). Family dysfunction can undermine the family's competence as a supportive entity for its members (Weihs et al 2002), resulting in an increased distress for those family members who have primary caregiving responsibilities (Scharlach et al 2006). Old loyalties and rivalries between siblings, problems and strengths stand out when a parent is in need of care. Conflict among siblings regarding the appropriate type and amount of support for the elderly care can override caregivers' normative expectations, arousing caregivers' frustration and anger (Semple 1992). Relationships among siblings, like the relationship between the carer and the elderly, do not arise afresh but are part of a natural continuum of the family's history (Brody 2004).

The relationship the carer maintains with her nuclear family (children and partner) is also an important component in the care experience. Caring for an elderly parent or parent-in-law means that time and attention is dedicated to the care work. The dependency of an elderly rebalances roles and relationships within the carer's nuclear family. Care can mean less time and attention for other aspects of life that may have received more attention from the carer, such as the nuclear family relationships. Whatever the pace of the readjustment, the caregiver's partner and their children may compete with the elderly for time and attention (Brody 2004). For the nuclear family, a main carer becomes a 'less-available mother', the 'always-tired partner', a source of constraints in taking vacations as a nuclear family, changes to the house infrastructure that affects the comfort of family members. Conflicts with the rest of the extended relatives (e.g. between carer's siblings), all affect the relationships within the nuclear family, affecting the caregiver in return and how she or he experiences caregiving as a result.

Like a specific context is not necessarily a resource or a constraint, a caregiver's social environment is not exclusively "good" or "bad". In every relationship there are, simultaneously, both positive and negative elements. The balance between the positives and negatives is different in different families and among different elderly and carer relations (Abel 1991). This overall balance determines the quality of relationships and, in the case of caregivers, configure their caring experience.

1.2 Research questions and objectives

As showed above, a micro- and macro-level approach to the study of elderly care complement each other for a comprehensive understanding of the phenomenon. This study will look at both dimensions of care in Chile. It will describe and analyse the policy context of care for the dependent elderly in Chile and exploring care as it is experienced by main caregivers. This study seeks to illuminate the path towards a more equitable distribution of elderly care, where the role of the government and different actors suits the experiences and demands of those who provide care to the elderly and dependent citizens.

These objectives are relevant given that, as will be shown, i) there is relative absence of public policies to support the provision of elderly care in Latin America, ii) most care for the elderly is currently provided by informal family caregivers with important implications for inequality, iii) there is a dearth of knowledge regarding the experiences of family caregivers of the elderly, and iv) the (lack of) connection between caregivers' experience and the emerging policy context.

Chile provides a good entry point to the study of both the experience of care and care policies in emerging economies as some argue it is approaching a care deficit and the government is only beginning to develop policies to face it. Chile offers a vantage point to analyse current approaches to care for other emerging economies to emulate or adapt. A deep understanding of care in Chile also allows for a critical appraisal of the current policy direction in the country and offer policy suggestions that are aligned to the provision and experience of care.

The study first explores how the elderly care is distributed in Chile and the government's role in assuming the responsibility for elderly care. It overviews the major steps, challenges and obstacles faced in developing public policies for care. The study then delves onto the care experience in the specific social, demographic and policy context of Chile. It explores what the family caregivers' experiences are and how tasks, potential context-related resources or constraints, the specific normative orientation and relational histories and contexts of caregivers determine their experience. Ultimately, the study sheds light onto how the government can adapt to caregivers' experiences and needs.

More specifically, and given the theoretical and contextual framework of elderly care discussed above, the study will first characterise the social and policy context of care in Chile. It will answer:

1. What are the characteristics of the elderly care phenomenon in Chile? Answering this question will allow to respond to who assumes the care responsibility and whether there is any care crisis and, if so, what is its nature.

A full characterisation of the elderly care context also requires understanding the public policies and programmes in place. We ask then,

2. What is the role of the government in Chile's elderly care regime, how has it evolved and what challenges does it face?

Despite advances in public policy for elderly care, governments in Latin America are very weak in providing elderly care or supporting families who care. In a context where the majority of care takes place inside households, an exploration of the phenomenon of care requires entering the private sphere:

3. Who and under what conditions and situations does the job of caring for the elderly?
4. What determines the intensity of the care experiences?
5. Can a qualitative approach to measuring the intensity of care identify what elements are missing from quantitative approaches to the study of care?

The answers to these questions provide a macro- and micro-level understanding of the care phenomenon in Chile. They will allow an informed discussion on the type of care regime in place in Chile and the direction the government can take to adapt to the current care scenario. In particular, they answer:

6. How can the role of the government adapt to the caregivers experiences and demands?

These research questions translate into the following research objectives:

a) Analyse the social organisation and the socioeconomic context of elderly care in Chile.
b) Examine the government's role over time and the challenges in adopting a more active role in elderly care.
c) Understand the caring experience and its intensity by the part of family carers
d) Orient elderly care policies in Chile given the findings of previous objectives.

In summary, by achieving these objectives, this thesis will contribute to a comprehensive understanding of the phenomenon of elderly care in Chile. The study of the analysis of the social distribution of care and the specific role of the government (macro-level analysis), will add to the knowledge of the Chilean care context and contribute to the discussion on the care regimes typologies in Latin America. The research will bring to light the experience of elderly care (micro-level analysis), understanding how their experience is shaped and lived. Taken together, these elements will help to adapt the current policies and government's role to better suit the needs of family (mostly women) elderly carers.

Chapter 2. Methodology

This study draws on different methodologies to answer the abovementioned research questions. The first section of this chapter details the methods used to describe the Chilean elderly care and its sociodemographic and policy context (macro-level analysis). The second section describes the methods used to understand the experience of care (micro-level analysis).

2.1 Chile's elderly care scenario and demographic and policy context

For the macro-level analysis, the thesis explores and analyses the magnitude of the elderly care phenomenon and the nature of a potential care crisis. It analyses and describes the policy context and the social distribution of the elderly care in Chile. A mixed-methods approach and several data sources are used. The study relies on the review of regional and national literature and political discourse, interviews with key informants in the area of elderly care and policies in Chile, all in addition to secondary data analysis of large-scale nationally-representative surveys. Quantitative and secondary data complement the secondary and primary qualitative data.

A descriptive quantitative analysis of large-scale surveys quantifies the demographic context and the elderly care scenario in Chile. These surveys used are:

1. The 2009 *Encuesta Nacional del Adulto Mayor* (National Study of the Elderly) conducted by the *Servicio Nacional del Adulto Mayor* (SENAMA, National Service for the Elderly.
2. The 2009 *Estudio Nacional de Dependencia* (National Study of Dependency) conducted by SENAMA.
3. The 2015 *Estudio de la Inclusión y Exclusión del Adulto Mayor* (Study of Inclusion and Exclusion of the Elderly) conducted by SENAMA.
4. The 2015 population projections by the Observatorio Demográfico de América Latina (Demographic Observatory of Latin America) by CEPAL-CELADE.
5. The 2015 *Encuesta Nacional de Caracterización Socioeconómica* (CASEN, National Survey of Socioeconomic Characterisation), a household survey conducted by the Ministry of Development.

The descriptive analysis was carried out using Stata 12. Reports from international organisations and non-for-profit and governmental organisations in Chile complement the analyses.

The Chilean policy context towards elderly care and its development is studied through a historical revision of the policy measures towards the elderly care. The identification of the main policy advances and challenges was carried out through a revision of official Chilean Government documents and reports, a revision of reports by international organisations, a revision of the public discourses and interviews with key informants in the area of elderly care.

Key informants' input complement the literature review and offer an updated account of the main policy challenges Chile faces with respect to elderly care.

All 18 key informants are directly related with elderly care and have a vast professional experience in the domain. They come from government agencies (seven informants), municipalities (four), universities (four) and private, public and non-for-profit elderly care service providers (three). All interviews were guided by a semi-directed interview based on a thematic interview guide (see Appendix I). The interviewer prompted specific questions depending on the specific background, technical expertise and professional experience of the key informant. All interviews were carried out by the same interviewer. The interviews lasted around one hour each and were held at the interviewee's workplace during working hours.

For some interviews (four), usually those of key informants working in groups on the implementation of programmes at the local level, there was more than one person in the room during the interview. The other people in the room sometimes contributed and enriched the discussion. This was not an impediment to the flow of the interview or the collection of expert information because points of view regarding the questions were often similar and complemented the key informants' answers and points of view.

The interviewer took field notes to describe the synthesis of the major themes that appeared along the conversations immediately after each interview.

All interviews were audio recorded and transcribed verbatim. All interview transcripts, field notes and all the literature pertaining to the policy context (official documents, discourses, scientific literature) were coded into ATLAS.ti with each code referring to the broader research questions surrounding the policy context. When quoting the original material that is in Spanish (as is the case, for example of official government documents and interview transcripts), quotes are first translated into English by the principal investigator (who also conducted and transcribed the interviews) and then included in the study. To protect the confidentiality of the key informants, quotes and opinions are referred according to their institutional affiliation or their professional title not their names. The following is the list of the offices or agencies represented by the key informants interviewed.

- National level policy design and implementation:
    - *Ministerio de Desarrollo Social* (MIDESO, Ministry of Social Development)
    - President's Office liaison point with the Ministry of Social Development
    - *Ministerio de Salud* (MINSAL, Ministry of Health)
    - *Servicio Nacional del Adulto Mayor* (SENAMA, National Service of the Elderly)
    - *Ministerio de la Mujer y la Equidad de Género* (Ministry of Women and Gender Equity).
    - *Programa de Adulto Mayor UC* (Centre for the Elderly at Pontificia Universidad Católica de Chile)

    - *Movimiento Pro-Emancipación de la la Mujer Chilena* (MEMCH, an NGO promoting women's rights)
    - Academic experts from Universidad Diego Portales and Universidad Alberto Hurtado
- Local level policy design and implementation
    - *Programa Cuidados Domiciliarios* (SENAMA's programme to offer respite and support to caregivers)
    - *Centros de Día* (SENAMA's programme to offer day care centres in collaboration with municipalities or private non-profit organisations)
    - Municipal offices in charge of the elderly
    - Primary health centres
    - Fundación Las Rosas (Non-profit residence for low-income elderly)

Interviews were carried out in March 2014, February-March 2015 and November 2015.

2.2 The experience of caregivers

An exploratory qualitative approach was adopted to explore the daily experiences of main family caregivers of elderly in need of care. It allows exploring a complex phenomenon, as is the experience of elderly care. Qualitative approaches allow to contextualize the phenomenon as it occurs in carer's ordinary environment. A qualitative method, as Van Manen (1999) affirms, is a technique of interpretation that can be used to describe or reflect social phenomena and allows to pay attention to the meaning of the phenomena rather than their frequency. In this qualitative orientation, research is directed toward understanding the reality from the viewpoints of the actors themselves as they are considered the authors of the social reality (Anadon and Guillemette 2007).

The qualitative approach used in this study is based on interpretative sociology to identify the experiences as felt by the carers themselves. Social actions – as, for example, elderly care –, are intelligible if, and only if, the subjective aspects of those who take part of those actions are understood (Weber 1978). The purpose of interpretive sociology and the qualitative methodology that stems from it is to understand the meanings that people give to their own lives and experiences. This is enabled by a qualitative design that draws on intersubjectivity – the collaboration between a researcher and social actors – which facilitates the understanding of complex issues (Habermas 1987) such as elderly care experiences. A joint effort between a researcher and social actors allows for deeper understanding of the phenomenon under study when compared to studies built exclusively from the point of view of the researcher and existing theories (Anadon and Guillemette 2007).

This study explores the experiences of care through the analysis of 42 cases of main family carers of an elderly parent or parent-in-law in need of care. The main carer is the one who provides assistance with both daily living and instrumental activities (Howe, Schofield and Herrman 1997). In situations in which part or all of the assistance is provided by externalised care, the main family carer is the one monitoring and organising care, rather than providing care directly (Campéon et al 2012). Main caregivers (also called primary caregivers) are usually not the only persons providing care, since others can also participate in the care arrangement in different forms. This research studies the experiences of the main caregiver, the one who has the highest level of responsibility regarding the elderly care and/or performed the largest number of caregiving tasks. This doesn't mean that the participation (or lack thereof) of other family or community members is not considered in the study; as will be seen, their involvement is related to the main carer's experience as well.[22]

Family carers correspond to a heterogeneous category (Arskey and Glendinning 2008) involved in the provision of direct care as well as in the coordination and organisation of care. Cases of this study follow this heterogeneity, they are daughters, daughters-in-law and sons of elders in need of care coming from different social and economic backgrounds.[23] As described below, the sample covers this heterogeneity.

Cases come from four municipalities of the Metropolitan Region of Santiago. The four municipalities cover different geographic areas of the city and have a diverse sociodemographic population profile.[24] Such sampling strategy captures a larger variety of cases in a more efficient way. Most of the cases were identified through professionals from the social and health sector in the different municipalities. The rest of the cases were gathered by snowballing among carers and through the principal investigators' personal contacts. To ensure their anonymity, fictitious names are used in this report. All interviewees read and signed a consent form agreeing to the use of their interview and photographs for this study (see Appendix III).

The sample is not intended as a representative sample of a particular population of carers. The sample selection criterion sought to obtain a deeper understanding of the care experiences from the perspective of different types of carers. Since care for a parent or a parent-in-law is a

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[22] Although other people (family, neighbours, community) may participate in the care arrangement, as shown in the sociodemographic context of elderly care in Chile in this study, most main carers do their caring jobs without any other sort of help or support (SENAMA 2009b).

[23] The majority of family carers are daughters and daughters-in-law. Partners (e.g. wives) are the second most common group of carers. This study pays particular importance to the relational nature of care. In considering the relational and emotional nature of care, partners' care experiences are a different phenomenon than that of children or children-in-law caring for their parents or parents-in-law.

[24] The Metropolitan Region of Chile is one of the country's 15 regions. The Metropolitan Region is situated near the centre of the country. It has a total population of 6,061,185 inhabitants, equivalent to 40.1% of the national population. This region is mostly urban, with a majority of middle class inhabitants. Across municipalities within the region, there is high cultural, social and economic variability. This study focuses on the urban population, where an 85.1% of the elderly population lives. Elderlies living in rural areas are not covered as the elderly living in the rural involve different situations and challenges. The geographical restriction of the sample to urban municipalities in the Metropolitan region ensures variability along the urban middle class in terms of socioeconomic dimensions and facilitates the data collection process. From the region's 52 municipalities, the study considers cases from the following four municipalities: La Florida, Santiago Centro, Puente Alto and Las Condes.

universal experience, men and women carers come from diverse backgrounds. As Brody (2004) notes, they are rich and poor, highly educated and uneducated, they vary in age and stage of life and stage of their caring career, some cohabit or not with the elderly parent or parent-in-law. This study's sample covers this heterogeneity by including carers from different socioeconomic and age groups, working status and family situations. One or two interviews per subject were conducted, depending on the information gathered in the first interview. A second interview allowed deepening and clarifying issues reported during the first interview. The first round of interviews was carried out in February-March 2015; the second round was carried out in November 2015.

Of the total 42 cases, six are carers of an elderly parent–in-law and the rest of the cases care for an elderly parent. Only three cases are male carers, all the rest women. Nine cases combine elderly care with part-time employment, six cases combine care with full-time employment. Eleven cases do not cohabit with the elderly, the rest live with the elderly. Eight cases belong to a high-income household, four to a high-medium income household, nineteen to a middle-income household, nine to a low-medium income household and two to a low-income household. Sixteen elderly under care by caregivers in the sample are severely physically or cognitively dependent; nineteen have a moderate level of dependency and eleven have a low level of dependency.[25] [26] Twelve carers in the sample combine elderly care with care for another family member, either a grandchild, a child or a dependent sibling. Appendix IV presents a characterisation of these cases and Appendix VII a summary of their narratives and histories.

The main data collection instrument is an interview guided by pre-established general and open-ended questions (Appendix II). The same interviewer carried out all interviews. The application of the questions did not follow a strict order. Depending on the emerging topics and topics covered, the interviewer prompted specific questions. Interviews were conducted at a time and place comfortable to the respondents (typically their home, but sometimes their workplace). Interviews lasted between 45 and 120 minutes. In some cases, the interview was carried out in

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[25] This sums to 46 elderlies with different dependency levels, and not the 42 carers in the sample because there were four carers in the sample who care for two elderlies simultaneously.

[26] The Barthel Index (Appendix V) is used to measure the dependency level of the elderly. It is currently used by primary health centres in Chile. The specific form was borrowed from the *Examen Annual de Medicina Preventiva del Adulto Mayor*, (Annual Preventive Exam for the Elderly). The Barthel Index is a simple scale to assess the overall functional status of an elderly. The scale consists of ten items and evaluates basic daily life activities, providing an index of autonomy-dependency in a short period of time (ten minutes maximum). The Barthel Index was asked at the beginning of each interview when this information was not provided by the professional who made the original contact or when the caregiver did not know the dependency level of the elderly. The caregiver's household's sociodemographic information was gathered through a short questionnaire borrowed from a social research firm Adimark. It combines the educational level of the head of the household and household possessions (e.g. internet connection, a car, etc) to estimate the household socioeconomic status. The application of this battery of questions takes, on average, seven minutes (Appendix IV)

the presence of the dependent elderly, this was usually the case when the carer cared for an elderly with dementia. Having the elderly around in the interview changed, to a certain extent, the dynamics of the interviews, as the interview was interrupted by the elderly or by interactions between the elderly and the caregiver. This situation provided additional information as it allowed the researcher to observe the dynamics of the relationship between the elderly and the carer. One interview (Lucy) was conducted in the presence of an elderly with only physical deterioration (no cognitive deterioration). Another interview (Victoria) was conducted in a room that allowed for the elderly (with no cognitive deterioration) to listen to the conversation. The main carers did not seem to restrict their opinions because of the presence of the elderlies during the interviews as personal and potentially conflictive issues were talked about freely.[27] [28]

All interviewees welcomed the researcher in a positive and open manner, as if they had long been waiting for the opportunity to talk and be heard about their experience as elderly carers, their everyday lives and their worries and rewards. The researcher often had the impression that the conversation was akin to therapy for the caregivers, who often expressed their relief and gratitude for the time spent together, and an opportunity to be heard. For many carers, the interview was interpreted as a rare recognition of the work they do and a rare interest in their lives and experience.[29] This situation posed a challenge to the researcher who had to remain neutral in front of people experiencing strong emotions. It was not uncommon for interviewees to cry out of sadness and desperation, or to cry out of pride and joy. It was therefore necessary to use discretion and delicacy to offer the opportunity for carers to be heard in a neutral manner.

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[27] Carers's apparent lack of inhibition to talk about their difficult experience with the elderly in hearing distance can be explained by the fact that carers had a pressing need to be heard and to talk about their experience, to the point that having the elderly around was not a problem. This lack of inhibition to talk about sensitive issues related to the elderly care in front of the elderly could be also explained by the perceived childishness of the elderlies due to the *role reversal*. It is not uncommon that, as adult children adopt caring responsibilities the main carer perceives the elderly as a child (Bastawrous 2011). In this case, the carer may feel like she could talk about anything as she feels the elderly is not going to understand.

[28] There is a generalised image that elderlies are like children, especially towards elderly with some physical or cognitive dependency. Not surprisingly and consistent with this image, elderlies feel they are not treated as they should and are not treated as they deserve. Elderlies in Chile perceive that the experience and wisdom that they have accumulated over the years are underused and not valued by the various actors in society (Thumala et al 2015). It is neither a coincidence that 73% of the Chilean population declares that people aged 60 years or older are unable to look after themselves, while only one in every four people in aged 60 or older have some degree of dependency (SENAMA 2009b).

[29] This need to be heard and the sort of therapy effect of the interview has also been noticed by other authors in the field of elderly care. Campéon et al. (2013) noticed that the carers of elderly parents with Alzheimer's disease had a strong need to share their life experience as carers, and that this was commonly accompanied by strong emotions such as sadness, madness, gratitude, pride, etc. Coudin (2004) noted that there was a demand by the caregivers interviewed that was not only about sharing the emotional dimensions of the caring experience, but also about finding organisational, physical, or financial counselling.

Special attention was given to not respond or ask questions loaded with any normative judgment.[30]

The interviewer wrote field notes directly after each interview. The notes describe the interview situation, the interviewer's appreciation of the caregiver's situation, a synthesis of the major themes that appeared to be important for understanding the caregiving experience, the interactions between the caregiver and the elderly and/or relatives during the interview and a summary of the overall interview.

Photography was used as a complementary data collection instrument. Harper (2002:13) notes how photography can complement research: "images evoke deeper elements of human consciousness than do words…" Harrison (2002) argues that photographs should be used in conjunction with an interview, they provide insight into memory and identity construction. The visual image is able to evoke emotions, abstract ideas, and the shared human experience (Hodges, Keeley and Grier 2000). In this study, photography is used as a complement to the interviews. It helped the researcher remember carers' facial expressions and the physical context where the interview took place, which often coincided with the physical context of the daily elderly care. They serve to humanise and synthesise the caregivers' experience.

The data analysis consisted on a revision of the full corpus of the interviews' audios, transcripts, field notes and photographs to get an immersion in the cases' experiences and to identify the essential themes for the description and interpretation of the experiences of caregivers.[31] The first stage of the analysis consisted in identifying essential themes related to each subject's situation and care experience. Codes were created from the collected data related to the essential themes that appeared. Codes were not extracted from previous research, as only few studies have dealt with the phenomenon of the experience of informal care in Chile. A second stage of analysis consisted in comparing the codes within the sample cases with findings from the international literature. The codes were used to systematically label and compare all instances of particular themes throughout the transcripts. The coding and analysis was carried out in ATLAS.ti.

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[30] The challenge was large. As the researcher, I sometimes felt sad and powerless myself in front of the difficult experiences of the caregivers I interviewed. Keeping a neutral posture was an important challenge because I was experiencing myself, as a researcher and a human being, strong emotions as well. This is a recognized difficulty of research interviews with sensible and / or weak subjects marked by a difficult life situation (Payet et al 2010). Being next to the caregivers, listening to their lives and bringing them into the recorder to then take them with me made me feel like as if I was taking advantage of their stories for the purposes of my own research, for my own interest. I tried to compensate these feelings thinking about the good I can do by making their realities visible.

[31] The essential themes are the aspects or qualities that make an experience how it is and without which the experience could not be what it is (van Manen 1990).

The quotations that are used along the document were translated from the Spanish transcription into English by the researcher who conducted the interviews. In order to make these translations more readable, where relevant, additional information within the quotes was added in square brackets.

Part Two: The Chilean context of elderly care

This second part of the thesis, composed of two chapters, presents the macro context of elderly care in Chile. It situates care in the specific social, demographic and policy context of Chile and positions Chile into a typology of care regime. Chapter 3 describes the sociodemographic context of elderly care in Chile; Chapter 4 delves deeper into the Latin American care regimes and into the Chilean policies, programmes and initiatives related to elderly care.

Chapter 3, describes the sociodemographic context of elderly care in Chile. It quantifies elderly care and the magnitude of the phenomenon in terms of a potential care crisis and in terms of the potential impact on social inequalities. It describes the elderly in Chile according to their social and economic characteristics and their need of care. It also describes the caregivers' characteristics and notes how the way care is distributed in Chile contributes to maintaining social inequalities in the country.

Chapter 4 then describes the organisation of care across different social actors (e.g. the family, the State, the community and the market) focusing specifically on the government's role. The chapter draws on care regime typologies to position Chile so to better understand the different societal actors' responsibility and roles in the provision of elderly care. It draws on a historical perspective to describe the evolution of policies and programmes in place to support care, identifying the obstacles and challenges that hinder the government from adopting a more predominant role.

In all, this second part delivers a comprehensive description and understanding of the elderly care context in Chile that will help to better understand the everyday care experiences explored in the Part Three of the thesis. Taken together, Parts Two and Three will allow for a comprehensive understanding of care for the elderly in Chile.[32]

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[32] To simplify reading and to avoid referring to "caring *for* and caring *about* an elderly parent" or "to care *for* and to care *about* an elderly parent", the texts uses the shorthand "caring *for* and elderly parent" or "to care *for* an elderly parent". Because it is a simplification, when the text refers to "caring for" or "to care for", this does not mean the situation does not involve "caring about" or "to care about".

Chapter 3. The sociodemographic context of elderly care in Chile

This chapter describes the demographic and socioeconomic context of the elderly in need of care and their carers in Chile. It is composed of four sections: i) Chile's demographic and social transition, ii) the elderly and the prevalence of dependency in Chile, iii) the characteristics of those who provide care to the dependent elderly, and iv) the gender and social inequalities associated to the provision of elderly care.

The chapter shows how there is an increasing demand for elderly care due to population aging and increased life expectancy. In addition, the provision of elderly care relies mainly on families and, within families, on women. Findings also point to the possibility that, in the coming years and decades, the number of women available to become family carers may decrease. Families in Chile are increasingly smaller and women are increasingly participating in the labour market. Although the demographic and social changes have already put pressure on an elderly care provision that relies on female family carers, this model of care has remained. Instead of relying on alternative forms of care, female caregivers tend to combine multiple roles (as paid employees and/or child caregivers in addition to elderly care). Commonly, solutions to this misalignment involve the women's withdrawal from the labour market among low and lower-middle sectors, lower fertility rates among middle and upper-income groups, or the reliance on very poor quality care services for low- and middle-income groups. None of these solutions are desirable ways to meet the increasing care demands. They all maintain and reproduce gender and socioeconomic inequality (CEPAL 2009).

The chapter also shows how a more equitable distribution of care among different actors of the Chilean society (e.g. the family, the State, the market and the community) is urgent. In the coming years, the pool of women available for care will not be enough to meet the increasing demand for care. Yet urgency is required because relying on women to take on that role makes them more susceptible to suffer social and economic deprivation, unless specific recognition and conciliation policies are put in place. The chapter also shows how reducing the care crisis to a deficit of women available to care vis à vis the demand for care is a narrow vision. It maintains the gendered nature of the care regime in place. The chapter thus shows that the nature of the care crisis in Chile is deeper and refers to the unequal social distribution of care more generally.

The demographic and socioeconomic context developed in this chapter draws on data from the *Estudio Nacional de Dependencia* (National Study on Dependency), carried out by the *Servicio Nacional del Adulto Mayor* (SENAMA, National Service for the Elderly) in 2009; the *Estudio*

Nacional del Adulto Mayor (National Study of the Elderly), also carried out by SENAMA in 2009; demographic projections calculated in 2015 by the Economic Commission for Latin America and the Caribbean (ECLAC), the *Encuesta de Caracterización Socioeconómica* Nacional (CASEN, National Socioeconomic Characterisation Survey), the *Encuesta Nacional de Mujer y Trabajo* (National Survey of Women and Work) conducted in 2012 by Comunidad Mujer and data from the Organisation for the Economic Co-operation and Development (OECD). Documents from international organisations, official documents from the Chilean government as well as scientific literature contribute as sources of information for this chapter's analysis.

3.1 Chile's demographic and social transition

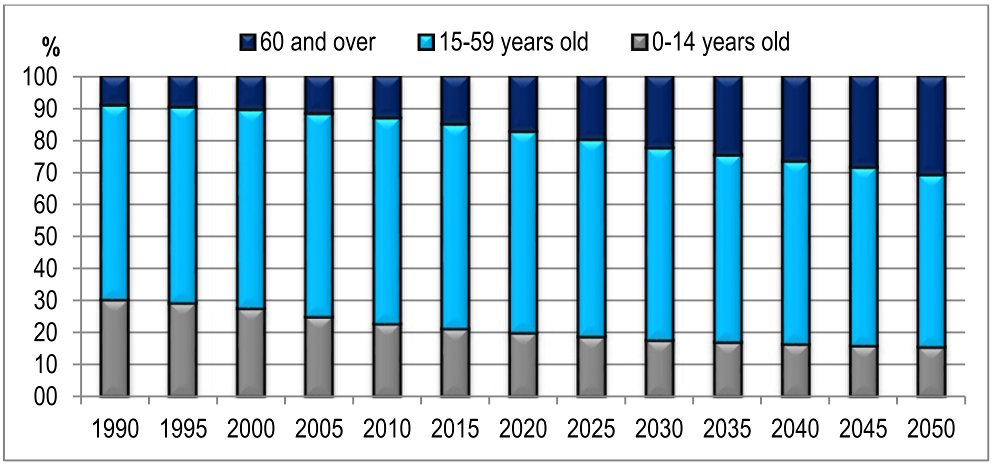
The Chilean population is aging, a successful outcome of the improvements in the health conditions of the population, scientific and technological advances, and the cultural, social, political and economic factors that have contributed to the decline in mortality rates, the consecutive increase in life expectancy and a reduction in fertility rates (SENAMA 2013). In parallel, socio-cultural changes such as women's access to birth control and their increased participation in the labour market have influenced a reduction in fertility rates.

The combination of these phenomena has led to a demographic transition towards an aging population, a transition in which Chile is positioned at an advanced stage (SENAMA 2013). In Latin America, Uruguay, Argentina and Cuba are at similar stages of this transition. Chile has the second oldest population in Latin America, with 15% of the population aged 60 or older. Life expectancy at birth is 82 years for women and 75.8 for men (CELADE 2015).

These changes in the age structure of the Chilean society took place in almost three decades, a faster demographic transformation compared to the one experienced by most developed countries. Chile's demographic transition was achieved at lower levels and progress in services, policies and development compared to European countries (Provoste 2012).

Figure 1 shows the rapid growth of the elderly population. In 1990, the elderly accounted for 9% of the population, while in 2015 it represented a 15%. CELADE (2015) projects that by 2020 the elderly will represent 20% of the total population. In 2020, the elderly will outnumber those under 15 years old, a situation never experienced by the Chilean society. Projections estimate that the percentage of elderlies will double that of the 15 year-olds or younger by 2050.

Figure 1 - Age structure of the Chilean population, 1990-2050



Source: CELADE (2015).

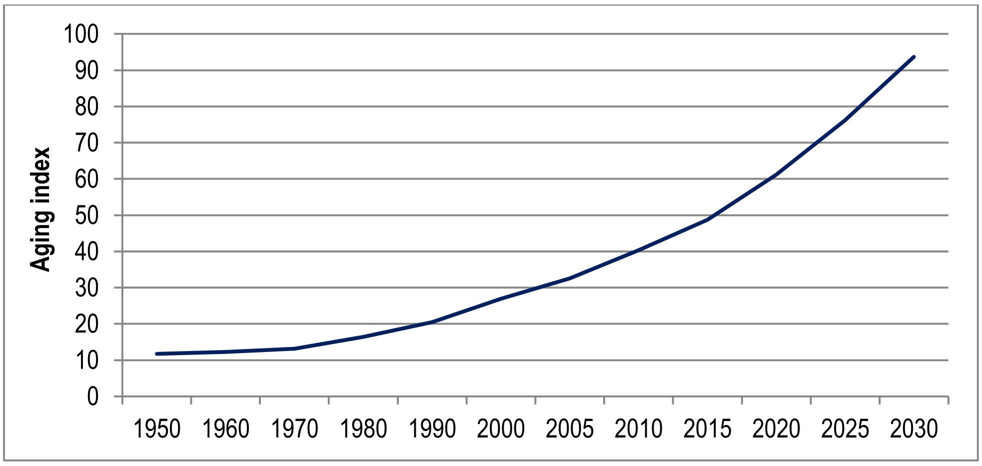
The increased share of elders in the Chilean population is in part due to a constant reduction in fertility rates. In the period between 1985 and 1990, for example, the fertility rate averaged 2.7 new-borns per woman. Between 2010 and 2015 there this figure stood at 1.8 births per woman, below the replacement rate of 2.1 (CELADE 2015).

The share of the elderly has also increased as a result of the fact that Chileans now live longer. In the 1970's, life expectancy at birth was 63.6 years; it rose to 78.6 years between 2005 and 2010. Life expectancy for people at the age of 60 has also increased: it was 17 years in the 1970s and reached 22.8 years in 2005 and 2010 (SENAMA 2009a).

This transformation has meant that, in Chile in 1950, there were 11.7 elderlies for every one hundred children under 15. In 2015 there were 49 elderlies per 100 children. In 2030, it is expected that there will be 94 elderlies every 100 children (Figure 2). This aging index has been constantly higher for women than for men, showing a higher proportion of elderly women over girls under 15 years old, than the proportion of men over 60 years old over boys under 15 years old (CELADE 2015).

Aging is a process of the individual life cycle that involves different levels of deterioration of the biological and cognitive functions (Thumala et al 2015). As the percentage of the elderly increases and they live longer, a larger proportion of society becomes fragile and in need of care. In an aging population, an increasing number of people depend on others to do their daily life activities (bathing, clothing, cooking, etc.), increasing the demand for every day care (CIEDESS 2013).

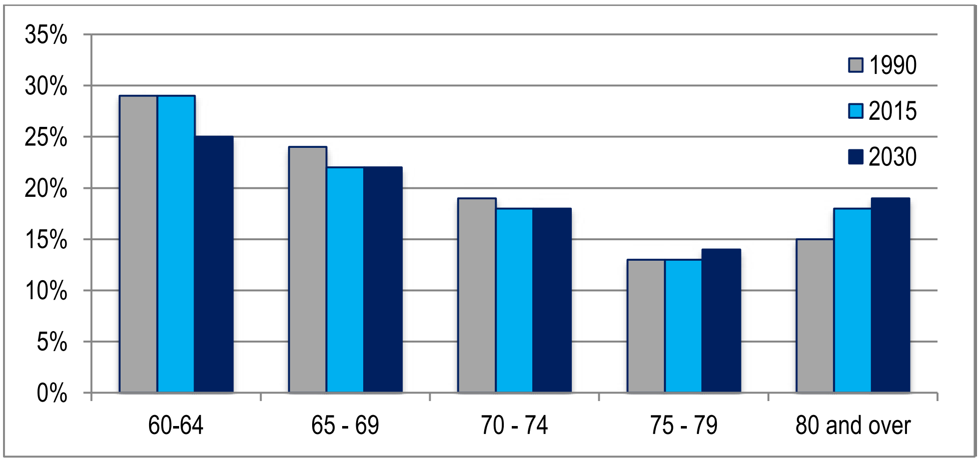
Figure 2 - Aging index of the Chilean population, 1950-2030



Note: The aging index is the number of persons 65 years old divided by the number of persons under age 15. The index is multiplied by one hundred.
Source: CELADE (2015).

The need for care increases rapidly among the elderly aged 80 or older. In Chile, in 1990, elderlies aged 80 or older represented 15% of the elderly population; they will represent an 18% of the elderly population in 2030 (Figure 3). The phenomenon of an aging elderly population will bring up more elderlies in need of complex care.

Figure 3 - Percentage of elderly by age group, 1990-2030

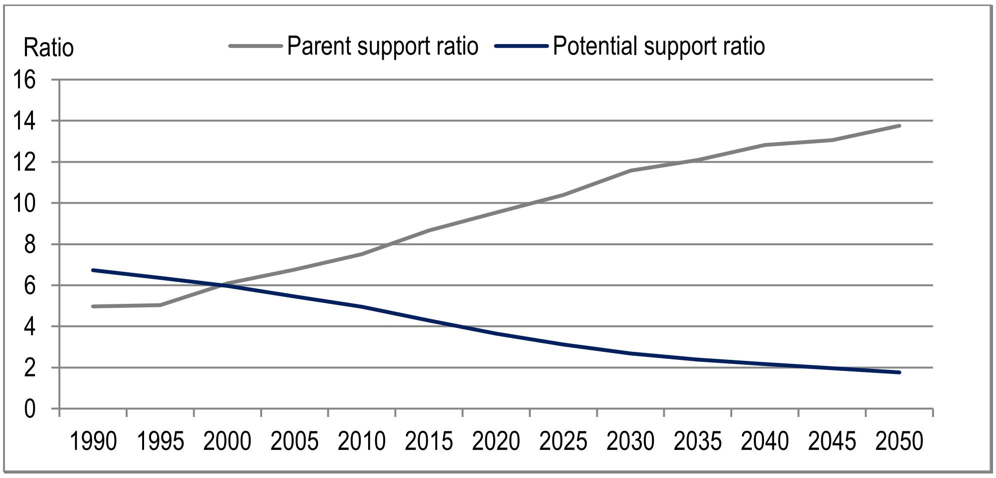


Source: CELADE (2015).

Estimates confirm that the increased future demand for elderly care takes place with an increased shortage of potential female family caregivers. The potential support ratio expresses the relationship between those more likely to be autonomous and economically productive (population aged 15 to 59) and those more likely to be physically and economically (population aged 60 or older). As Figure 4 shows, the potential support ratio decreased from 7% in 1990 to 4% in 2015 and is expected to reach 2% in 2050.

The parent-support ratio shows the shortening of the difference between potential caregivers and elderly people who might need care. It is a more appropriate measure to illustrate the potential elderly care deficit projected for Chile. It is the number of persons aged 80 or older per one hundred persons aged 50 to 64 years.[33] As people are now living longer than in the 1990s, there are (and will be) more and more people in their fifties and sixties likely to have surviving parents. In Chile, as shown by the grey line in Figure 4, there were fewer than five persons over 80 years per hundred persons 50-64 in 1990. By 2015, this ratio had almost doubled, to reach nine persons over 80 years per hundred persons 50-64, and by 2050 it is expected to be equal fifteen (CELADE 2015).

Figure 4 - Parent-support ratio and potential-support ratio, 1990-2050



Note: The parent-support ratio is the number of people aged 80 or older divided by the number of people aged 50 to 64 [((population 80 and over)/population 50-64 years old)*100]. The potential-support ratio is the population of 60 or over divided by the population aged 15 to 59 [((population 15-59)/(population 60 and over)].
Source: CELADE (2015).

Other estimates also show a decrease in the potential number of family members available. The increase in the labour participation of women, a decrease in household size and change in family structures (e.g. more single-headed households and fewer children per household) relate to a change in the current and future disposition of women to be the caregivers of the elderly family members.

Single-parent households were 34% of Chilean households in 2015, up from 22% in 1990 (CASEN 2015). There are now more households with fewer adults caring for its dependent members. Furthermore, the increase in single-parent households goes by hand with a high share of female-headed households among the single-parent households, at 87.7% (CASEN 2015). Many of these women have to combine caring tasks with work outside their homes.

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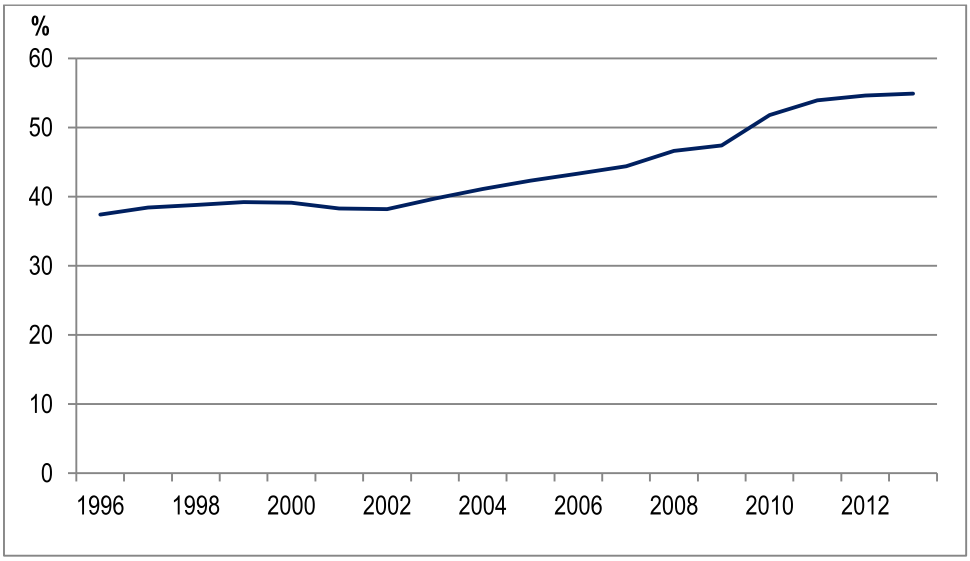
[33] The parent-support ratio estimates the demands on families to provide care for their oldest-elderly members. It relates the elderlies to their presumed offspring, who were born when the older persons were in their twenties and thirties. However, since the people in the numerator and those in the denominator are not necessarily related by kinship ties, the parent-support ratio should be taken only as a rough indicator of changes in the family support system required for the oldest-old (Kinsella and Taeuber 1993).

Adults today have fewer children that could become their carers when they age. Families are also smaller in Chile now than in the past. Households have now an average of 3.4 members (CASEN 2015). Women have, on average, 1.8 children, down from 2.0 in 2000 and 2.5 in 1990 (CELADE 2015).

The tendency in fertility rates is crossed by socioeconomic differences that affect elderly care in different ways across socioeconomic groups. The reduction in the fertility rate is stronger among higher socioeconomic groups, this may be due to the awareness that it is very difficult to enter the labour market and combine childcaring tasks, as the access to care services in the market is expensive. On the other hand, the higher fertility rates in lower socioeconomic classes, means that families from the lower classes have to care for more family members, decreasing their possibilities to access to the labour market, support their income and exit or protect against poverty.

Nowadays, more Chilean women are in the labour market as compared to previous years. Women's labour force participation (WLFP) has increased 17.5 percentage points since 1996 (Figure 5). The increasing share of women's participation in the workforce also puts pressure in the current care arrangements that depend on the family, because kinship networks, daughters and daughters-in-law have less time available to provide care to their dependent relatives (Arriagada 2009).

Figure 5 - Female participation in the labour market, 1996-2013



Note: Labour force participation is calculated based over the female population aged 15-64.
Source: OECD Labour Force Participation Database 2013, (OECD 2013a).

Even though more women are in the labour market, there is no evidence for a comparable increase in men's participation in caring tasks and domestic work. The rigid gender distribution of work inside Chilean households remains despite changes in employment and labour force participation (Arriagada 2011). It can be challenging or complicated for working-age caregivers to combine paid work with caring work and home tasks.

It is important to notice that, although more women are entering the labour market, Chile lags other developed countries, as the WLFP is still not only lower in Chile than in most OECD countries but also one of the lowest among Latin American countries. Furthermore, the WLFP is unequally distributed among the Chilean women, since only three out of every ten women from the lowest socioeconomic groups are in the labour market (Novella et al 2015), a difference strongly related to caring responsibilities. More about the social inequalities related to the elderly care are discussed at the end of this chapter.

In Chile, it is not common to combine a paid activity with care, and most family caregivers are exclusively dedicated to care (Comunidad Mujer 2012). However, there is still a number of people that balance care and work in their lives, and a growing number of women in the labour market combine paid employment with their role as caregivers. Comunidad Mujer (2012) estimates that 11% of women in the labour market have a dependent family member (children, elderly and or disabled person) under their care. For those women able or forced to combine care work and a paid activity, the combination of both activities is ether possible by paying an external caregiver or by juggling to balance both responsibilities.

3.2 The elderly and the prevalence of dependency in Chile

The World Health Organisation classifies the elderly as people who are 60 years or older in developing regions, and people aged 65 years or older in developed regions (WHO 2013). Following this classification, a person older than 60, female or male, is considered an elderly in Chile. Following trends in other countries, among the elderly the percentage of women is higher when compared to that of men (63% women and 37% men).

In terms of income, elderly men receive, on average, 229,574 Chilean pesos (approximately 330 euros)[34] a month; elderly women receive 178,367 pesos (255 euros) with most of this income coming from retirement pensions (CASEN 2013). The monthly minimum wage in Chile was 250,000 pesos (approximately 360 euros) in early 2016. Only one in five elderly has a monthly income equivalent to more than 300 euros per month. For elderlies from the first quintile of the income distribution (the most financially deprived), 49% of their monthly income comes from government subsidies. Only 1% of income of the elderly in fifth quintile comes from subsidies. The generally low monthly income/pensions elderly receive do not allow the majority of them to ensure their welfare. Their pensions do not allow them to access the market and access formal

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[34] Amounts in Chilean Pesos reflect figures at the time of data collection. Amounts in Euros are approximate given the fluctuations in the exchange rates. Amounts in Chilean Pesos are converted using a 1 EUR = 700 CLP exchange rate and rounded to facilitate interpretation.

care or to compensate in a monetary way those who take care of them informally. For the majority of the elderly, their income does not allow them to live in a different household than that of their children or other family members (Chapter 4 provides more detail on pensions in Chile and its implications).

As age increases, so does the likelihood of needing care, as the limitations for carrying out daily life activities (DLA) and instrumental life activities (IDLA) increases.[35] The prevalence of the need for care given limitations for carrying out DLA is 33% among women and 27% among men. The most common limitations are not being able to go out alone (21%) or do the groceries (21%). The least common limitation is managing their own money, where only an 8% of elders reported difficulties with this activity (SENAMA 2009b).

The difficulties in doing daily and instrumental life activities reflect the dependency level of the elderlies. The level of dependency measured by SENAMA's National Study on Dependency considers the functional capacity of the elderly to carry out daily and instrumental daily life activities by their own and the type and amount of help needed from others. Calculated this way, dependency is a continuum that goes from low to severe, and most of the dependent elderly in Chile have severe dependency.[36] Among people aged 60 years or older, 24% have a physical or cognitive dependency. Of the dependent in this group, 66% are women and 34% are men. Among the elderly with some level of dependency, 51% show severe dependency, 21% show moderate dependency and 28% show low dependency (SENAMA 2009b).

As expected, dependency is more prevalent as age increases. While 17% of those aged 60 to 74 years old present some dependency level, 39% of those 75 to 84 years old do and 74% of all the elderly aged 85 or older depend on others for carrying out daily or instrumental life activities (Figure 6). This figure is particularly important in the elderly care context because the proportion of the elderly population over 80 years old, as previously mentioned, is expected to increase. In the coming decades, the proportion of elderly in need of care will likely increase.

Considering that the Chilean population is now living longer and that there are and will be a higher number of elderlies in advanced aged, it is very likely that a higher proportion of the elderly have some level of dependency.

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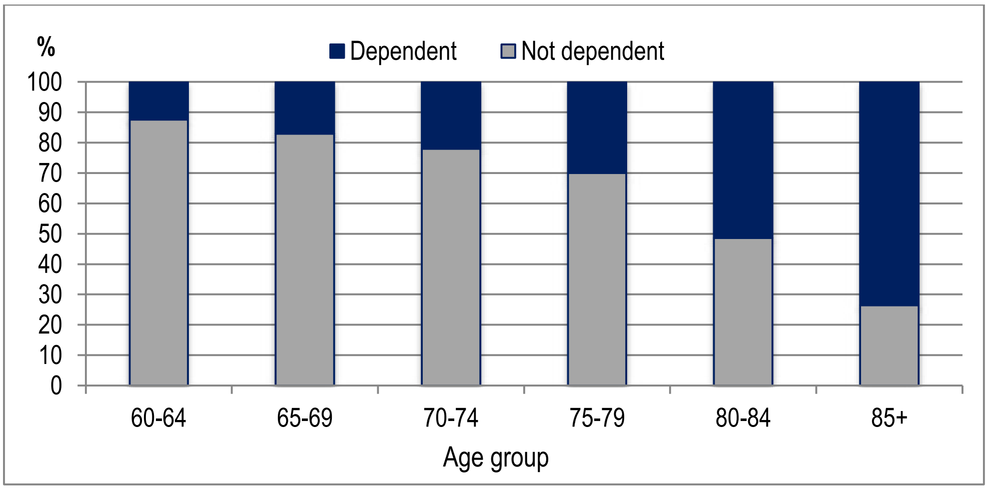
[35] Daily life activities include getting dressed, bathing, eating, getting in and out of bed and going to the toilet. Instrumental daily life activities include preparing hot food, managing their own money, going out alone, doing the groceries, making and receiving phone calls, cleaning the house, and organizing and taking their medications.

[36] SENAMA, primary health centres and this study use the Barthel Index to measure dependency (see Appendix V).

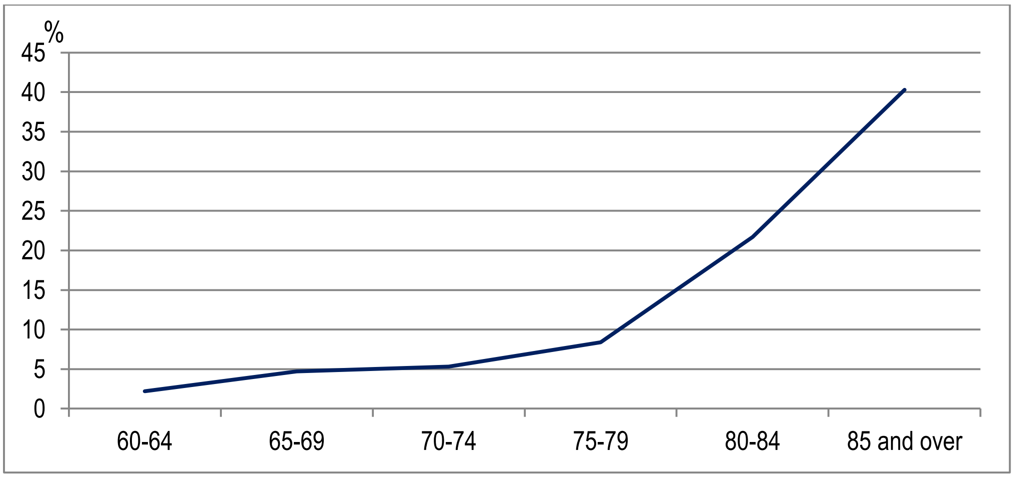
Figure 6 - Prevalence of dependency among the elderly by age group



Source: *Estudio Nacional de Dependencia,* SENAMA (2009b).

The challenge associated with the future care scenario is not only an increase in the number of people that will need care, but also that this care will be more complex. The dependency due to a cognitive impairment (usually a type of dementia) increases with age and it does so exponentially after age 75. In Chile, cognitive impairment affects more that 40% of the elderlies who are over 85 years old (Figure 7). Chronic diseases and comorbidities (having more than one disease) also become more common as age increases. Chronic diseases are prevalent in three of every four elderly. More than a third of the elderly have one chronic disease, 22% have two chronic diseases, and a 0.4% declared having more than six. Hypertension, diabetes, and respiratory diseases are the most prevalent chronic diseases reported by Chilean elders (SENAMA 2009a). Comorbidity and chronic disease also imply a more sophisticated type of care.

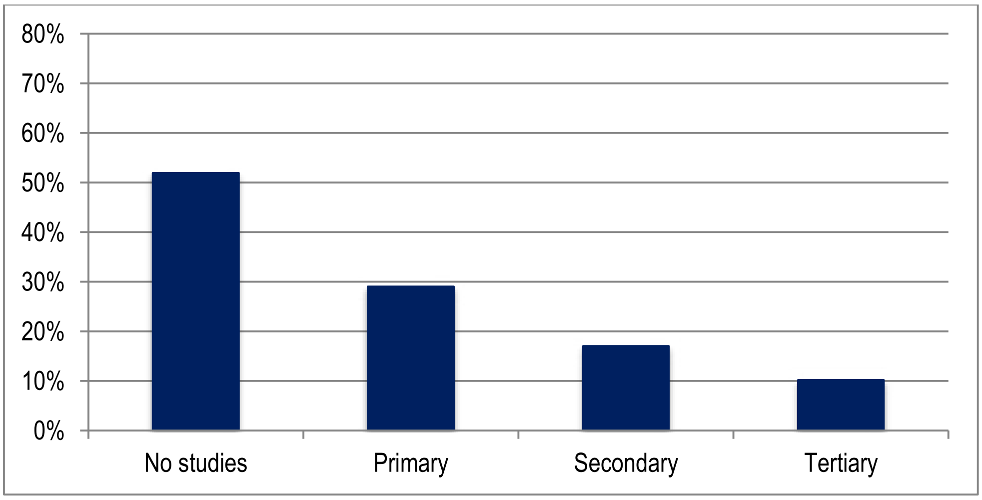
Figure 7 - Prevalence of cognitive impairment by age



Source: *Estudio Nacional de Dependencia,* SENAMA (2009b).

The prevalence of dependency does not only have a differential distribution across age groups in old age. There are equity-related differences in its distribution as the prevalence of dependency has an unequal distribution across socioeconomic groups. Dependency is more common among elders with a lower educational attainment than among more educated elders. A similar negative relationship is observed between dependency and income level, as elders with a higher income level show lower levels of dependency. This implies that those elderly in need of care are, in most cases, those that do not have the means for accessing to professional care in the market, therefore relying solely on family members, usually under an informal and unpaid work arrangement.

Figure 8 - Share of dependency by educational attainment among the elder



Note: Tertiary includes individuals who entered, completing or not, tertiary education.
Source: *Estudio Nacional de Dependencia,* SENAMA (2009b)

The majority of the dependent elderly live with someone else (85%); 15% lives alone. The likelihood of an elder living with someone else increases with the level of dependency: 84% of the non-dependent elderly live with someone else, this is the case among 88% of the elderly with low or moderate dependency, and 92% of those with severe dependency.

In summary, 24% of the elderly population in Chile depends on others for carrying out daily and instrumental like activities. Dependency is unequally distributed among the elderly population, as it is more prevalent among women than men, and people with lower socioeconomic status have a higher likelihood of experiencing dependency than those with a relatively high socioeconomic status. Dependency is also more prevalent as age increases. A very low percentage of dependent elderlies live alone, and this percentage becomes lower as dependency level increases.

3.3 Care provision for the dependent elderly

Despite the social, economic and cultural changes of the last decades in Chile, the family continues to be the institution in charge of providing elderly care (Batthyány 2009). Data from the National Study of the Elderly in Chile (SENAMA 2009a) shows that elderly care in Chile is informal, unpaid, family-based and gender-biased.

For almost 92% of the dependent elderly, it is a relative who provides care through an informal arrangement.[37] Around 10% of the dependent elderly are under the formal care of a person or entity (e.g. nursing homes) through a paid or unpaid agreement. Nursing homes in Chile are usually administrated by not-for-profit organisations (most of them are faith-based institutions) but some for-profit nursing homes exist. In the former cases, the elderly pays a monthly payment according to their family income, in the latter, prices are set according to the functionality profile of the elderly and their room preferences (single or shared room). The monthly cost of a nursing home ranges from 220,000 pesos to 2 million pesos (315 euros and 2,850 euros). Given the earnings distribution in Chile, only high-middle income and high-income families can pay for them (SENAMA 2009c).

In 2011, there were 664 elderly residences authorized by the Ministry of Health. This number fails to meet the demand, promoting the creation of low quality clandestine nursing homes (Arriagada 2011). Marín et al (2004) find that the proportion of institutionalized elderly was 1.6% of the total elderly population (their estimates include elderlies with and without a dependency condition). They estimated that in the Santiago Area, only 40% of the existent elderly insititutions were registered at the Ministry of Health.

Women provide the majority of informal care in Chile. Of the total informal caregivers of the dependent elderly, 86% are female and 14% male. Care for the dependent elderly is provided mostly by daughters, followed by wives. Only 2% of the dependent elderly population is under the care of paid domestic service provided by non-family members. Migrant caregivers (mainly from neighbouring Peru) have an increasing participation in this market, but although their participation is increasing, only a 4% of home care (for both the elderly and children), was provided by migrants (Stefoni 2009).

The great majority of caregivers are between 35 and 54 years old, a group usually considered prime age workers, since it is the most productive age at work. Yet, 72% of the elderly caregivers in Chile are not in the labour market. In addition, women within this age group have a higher probabily of having a dependent child under their care too. This means that many

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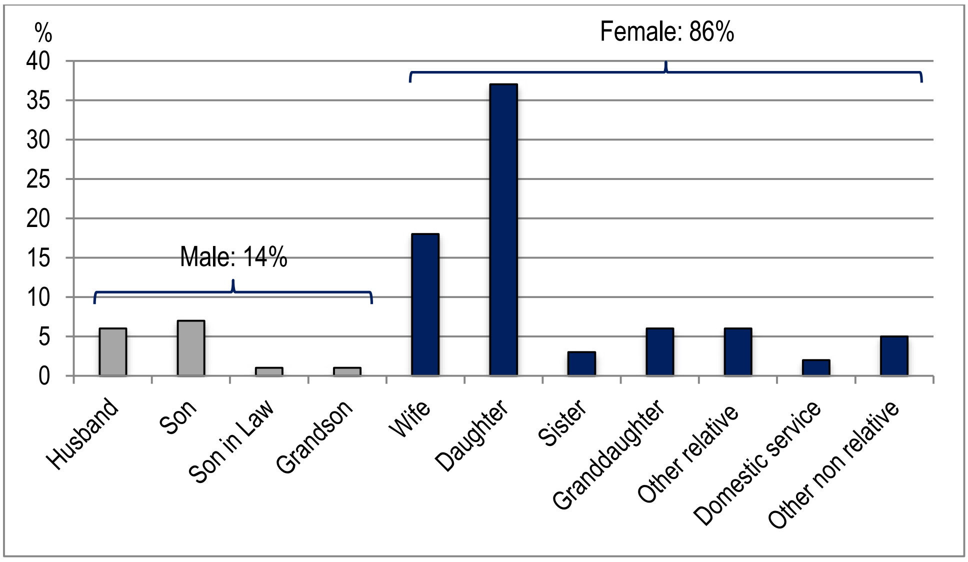
[37] Informal caregivers is a terminology used often to refer to family carers, but, strictly speaking, this category includes also paid caregivers who are undeclared to social security and therefore work outside the context of formal employment regulations (Colombo et al 2011).

adults, who have the responsibility of caring for their aging parents, have the added responsibility of caring for their own children. Often this requires the caregiver to juggle the competing demands of family caregiving with employment and parenting their own children. As illustrated with more detail in Chapter 5, these multiple responsibilities may lead to role conflict and role strain within the family or between the family and the job (Durant and Ollie, 2006), but may also offer respite for elderly caregivers.

Figure 9 - Relationship between the main caregiver and the elderly



Source: *Estudio Nacional de Dependencia,* SENAMA (2009b).

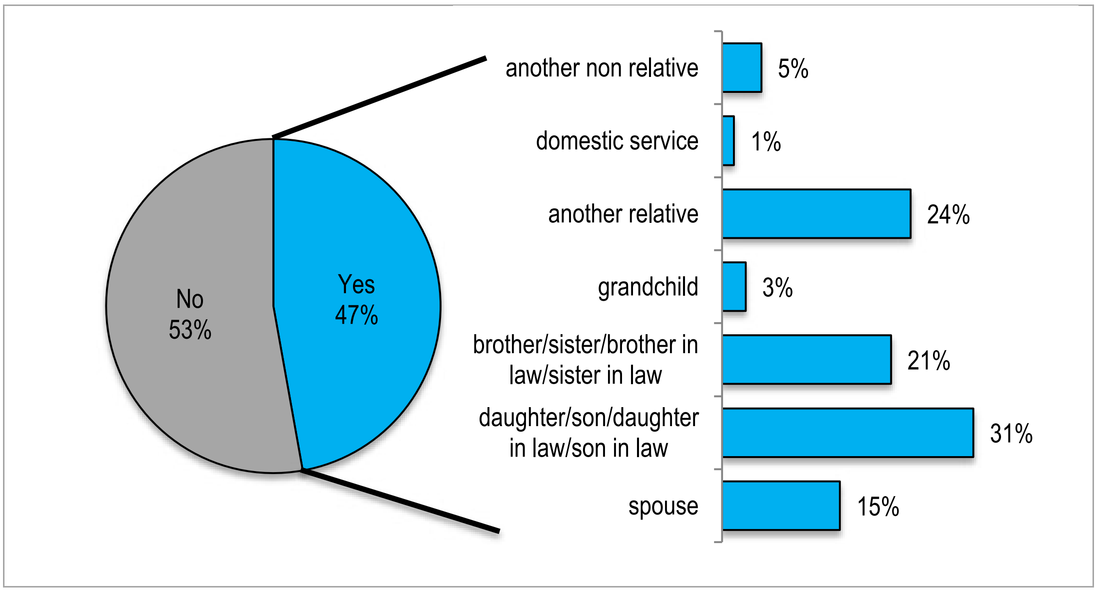
The National Study of Dependency of the elderly (SENAMA 2009b), in an attempt to measure the burden that care means for their caregivers, shows that family caregivers are very likely to report “being overwhelmed in their situation”, “feeling alone”; “that they do not receive support”, “that they do not have access to holidays” or that they are “not able to take leave from their tasks”. Most caregivers devote their daily life caring for the elderly: two thirds of them have not taken vacations in more than 5 years. The majority of the caregivers have been taking care of the elderly for more than a year, and only 18% has been caring for less than one year. A caregiver works, on average 16 hours per day fulfilling care duties, and a 72% of them provide care to the elderly during both the day and night.

Regarding the provision of home tasks like cleaning, cooking or doing the groceries, a 53% of caregivers report that they do not share these home-related tasks with anyone else, meaning that in addition to their direct caring tasks, caregivers are also likely to carry out all the home-related tasks without any form of support.

Only 8% of caregivers receive monetary compensation for their care work. This compensation is amount to less than half of the minimum wage.

The majority of main caregivers (53%) do not share caring tasks with any other person. Among those who do receive support, share caring tasks with a daughter or son (31% of those who share) and only 1% share caring tasks with an external paid caregiver (domestic service).

Figure 10 - Proportion of caregivers who share caring tasks and people with whom tasks are shared



Source: *Estudio Nacional de Dependencia,* SENAMA (2009b)

On average, caregivers have six years of formal education, and only a 5% of them have obtained a professional degree. Added to this low number of years of education, and considering that care needs are more complex (as the elderly are living longer and the life expectancy for those with chronic diseases has increased), only 8% of caregivers have received a training programme specifically related to elderly care. Out of the small number of caregivers who have received training, 97% agreed that it was very helpful.

These figures provide a rough outline of who provides care and an extremely rough outline of how care is experienced. Little is known in Chile about the daily life experience of family carers of the elderly, about how they experience the lack of support, the long hours of care work, the forgone vacations, the ‘decision’ to become caregivers, the fact that they combine (or do not combine) elderly care with a paid employment, etc. Part Three of this study provides a comprehensive understanding of the experience of care from the point of view of caregivers themselves.

3.4 The gender and social inequalities associated to the elderly care

The current social distribution of elderly care carries with it the transmission and maintenance of social inequalities associated to care. The potential care deficit of elderlies in need of care in relation to female family members to care for them is not, by itself, the most challenging subject related to elderly care in Chile. A proper management of elderly care in Chile requires examining the care crisis with a broader perspective. From this broader perspective, the care crisis refers to the deficit in the private sphere, in relation to the absence of people and support networks to ensure the care of dependent family members, but also to a deficit in the public sphere, in relation to the lack of policies and the dearth of government attention to the issue. The care crisis also results from the weak appreciation of the care activity. It is rarely considered a job, especially if it is carried out inside the doors of a home. Care is also socially devalued and invisible because it is carried out mainly by women, and because as a society people who need care are devalued, especially if they are part of a group with weak political power and visibility, such as the elderly, the disabled and the chronically ill (Acosta 2015).

Given the gendered cultural norms and the weak government role in providing elderly care alternatives (see Chapter 4), it is very likely that women will provide care. For high-income women, the care crisis would be a matter of deficit, since there is a threat to the traditional family (female) care arrangements. The higher entrance of high income women to the labour market, given their levels of education and the potential returns of the market that could allow them to access to market services and elderly care could imply higher opportunity costs for them to enter the labour force (Mosca et al 2016). On the other side, for those who don't have any other option available for providing care to their elderly relatives (market access is impossible even if entering the labour force since the potential salaries they may receive are not enough to pay for formal care), the challenge and the real crisis of the situation is the inequity and the conditions under which they provide care. For CEPAL (2009), it is necessary to move beyond characterising the care crisis as an addition and subtraction of care required (the demand for care) and caregivers available (the offer of caregivers). The real problem is indeed of social and gender nature (Montaño 2004) and an opportunity for a more equal distribution of care responsibilities among the society across gender and social actors (Provoste 2012).

The higher the amount of care left to families, the greater the role that socioeconomic and gender differences play in determining who, and in what conditions, provides care. Given the gender-biased obligation to care and the ability to access the market, care regimes that rely almost exclusively on families maintain gender and socioeconomic inequalities (Saraceno 2010, Saraceno and Keck 2010).

In Chile, as in the rest of Latin America, social inequalities are closely linked to the unequal provision of family care forming a vicious circle: those with more resources have greater access to quality care, in circumstances that they have fewer household members to care for. Those who have fewer financial resources to access paid care accumulate disadvantages by dedicating more time to caring responsibilities and less time to a formal and paid job, in a context of scarce access to public services (Aguirre 2007). Orozco (2010) goes further, stating that as care is neither socially not publicly valued, care provision lies on those who have a smaller capacity of choice or decision.

Pautassi (2008) points out that the issue of care and who provides it necessarily refers to a problem of exercise of rights and reproduction of inequalities. The gender imbalance that accompanies the provision of care is largely founded on the belief that women have a natural endowment to perform these tasks. Care lacks social valuation, which is closely related to the rights of those involved in the provision of care and the possibilities and conditions under which they exercise citizenship. Glenn (2000) provides an analysis of the scope of the concept of citizenship in the context of care (citizenship as the full membership in the community including reciprocal rights and responsibility in the phenomenon of care). The concept of *citizen* involves a public-private dichotomy, which relegates the private sphere not only outside the public world but also in opposition to it. Care work performed in the private sphere is outside society and citizenship. The relegation of care to the private sphere and its consecutive devaluation, contribute to the marginalization, exploitation, and dependency of caregivers (Glenn 2000).

There are important gender inequalities in Chile. Women's labour participation is 30 percentage points below that of men's. Women are over-represented among those who work on a part-time basis: 45% women aged 25 to 59 are engaged in part-time jobs but 25% of men of that age group are (Comunidad Mujer 2016). While women's labour force participation has increased since 1990, for Del Valle (2011) there is a paradox or a contradiction between the increasing female labour participation in Chile and the slow or inexistent changes in the gender division of care tasks. The stagnation of gender roles in care tasks are culturally rooted and do not reflect Chile's economic development.

Gender inequalities interact with socioeconomic inequality. Labour force participation rates among women from lower-income households remain on average 40 percent below that of women from higher-income households, often due to their difficulties in resolving their care responsibilities (CEPAL 2009). While 84% of women from the highest decile of the income distribution are in employment, only 46% of women from the poorest decile are engaged in employment. The likelihood that families overcome poverty is closely linked with the presence of at least two income earners (OIT and PNUD 2009). Women's inability to participate in the labour market reduces the income of already low-income households, aggravating poverty and social inequality (CEPAL 2009). Finally, among female-headed single-parent households, many of these trends are exacerbated by the fact that women are solely responsible for providing both income and care.

The Chilean labour legislation assumes that women are responsible for their children's care by imposing obligations on the employers of female workers (e.g. the obligation to support childcare). As it is more costly for employers to hire women, women experience a disadvantage in the labour market. They have more difficulty landing a job and earn lower wages. Also, wages are usually lower than reservation wages (the minimum wage at which a worker would accept employment) reducing women's motivation to search for employment altogether. And cultural values dictate that men should take on paid employment and women should be in charge of domestic and caring-related activities, thus reinforcing the sexual division of labour. All these factors – many of which are directly related to care – contribute to explaining the low participation of Chilean women in the labour force in relation to other OECD and Latin American countries and the corresponding gender inequalities (Comunidad Mujer 2016).

Furthermore and irrespective of gender, the possibilities of getting a job that will pay a sufficiently high salary to pay for externalized care in full or in part are very low. OECD (2015b) notes that earnings quality (an indicator of the extent to which employment contributes to meeting the material living standards of workers and their families) is lower in Chile than the OECD countries' average. Though Chile's GDP has grown in the past decades, it has done so unequally. Income distribution in Chile is one of the most unequal in the world. Only a small part of the Chilean population earn wages that would allow them to externalise part or all direct care responsibilities. The economic inequalities segment the access via the market to care services in a context of public lack of protection (OIT and PNUD 2009). As described in Chapter 4, this reality, in addition to a scenario of only recent government support in terms of elderly care and social policies means that a significant part of the Chilean population can neither access care services in the market or qualify for the State support.

3.5 Conclusions

Some 24% of the elderly population in Chile are in need of care. They have a cognitive or physical deterioration that limits their ability to carry out instrumental or daily life activities. The prevalence of dependency increases with age. Dependency is also more common among elderlies with lower levels of education and among female elderlies. Some 90% of the dependent elderly are cared by a family member or through an informal arrangement; only 10% receive care at an institution. 86% of informal family caregivers are women. Most of them are daughters, followed by wives. Most of them are in working age, as they are between the ages of 35 and 54.

Projections point to a larger proportion of elderly population, situating Chile in an advanced stage of the aging processes. This tendency is the result of a growing proportion of elderly population due to a decrease in mortality rates and the increasing life expectancy of the population. Along with this demographic changes there is also the tendency of a decreased number of potential caregivers, as families are smaller, single households increase and women are have increased their participation in the labour market.

The increase in the number of elderlies in need of care and the decrease in the potential caregivers have led others to refer to a potential care crisis in Chile. However, the most substantial factor related to the care crisis and to the magnitude of the phenomenon are the social and economic inequalities associated to care, not the relative shortage of women to care for the growing number of elderly.

As described in Chapter 4, the care crisis is the unequal social distribution of care. Families take on the social responsibility for elderly care. The unequal provision of family care in a context of little support from the government maintains a vicious circle of inequalities: those with more resources have more probabilities to enter the labour market and have greater access to quality care services and support, also in circumstances in which they have fewer household members to care for. Those who have fewer financial resources to access paid care accumulate disadvantage by dedicating more time to caring responsibilities and less time to a formal and paid job. As Montaño (2004) pointed, the care crises problem is indeed one of social and gender nature. Provoste (2012) adds that in this changing demographic and social care scenario, societies haven't yet seen an opportunity for an equal distribution of care responsibilities across different actors in society.

As shown in this chapter, 90% of the elderly in need of care in Chile are under the responsibility of a family member (86% of them women). These figures suggest that Chile is a primarily *familialistic* welfare regime. This figure, however, does not speak to whether familialism in Chile is *unsupported* or *by default*. Following Martin's (2015) point of view, the strong role of the family solidarity as those present in *unsupported familialism* regimes is the result of the absence of State support, because without this support, families are *forced and required* to assume many caring responsibilities. They *have to do so* as there isn't any real alternative. But in the context of a rapidly developing country like Chile, policy attention to elderly care is increasing and programmes and services are beginning to be offered. What alternatives are being developed by the Chilean government to support or alleviate families in caring responsibilities? Are they enough to consider Chile's welfare regime as one that is not *unsupported familialism*? The following chapter details the historical and current role of the Chilean government as to face the elderly care phenomenon.

Chapter 4. The policy context of elderly care in Chile

In the context of Latin American countries, the role of the Chilean State in the welfare system has been labelled as a *state productivist*, one in which informal arrangements interact with public policy focalised on families who cannot access welfare in the market or by themselves. It is also called a *market-centred* regime characterised by an accelerated shift from the State to the private provision of services, in particular health, education and pensions (Sunkel 2007). In Chile, families are largely responsible for providing welfare and social protection to its members. The State intervenes only in cases of vulnerability. In this regard, elderly care is mainly provided by families, and within families, by women. From the perspective of elderly care, and despite public policy efforts, this chapter concludes that Chile's welfare regime is an *unsupported familialistic regime*.

The State began to adopt a more active role since the return of democracy in the 1990s, focusing on the needs of the most vulnerable population and slowly increasing the scope of social policies to other groups. The State acts to protect individuals who live in vulnerable conditions.

The Ministry of Social Development (MIDESO, formerly MIDEPLAN) defines vulnerability as the risk of being in poverty,[38] which includes both households currently living under the poverty thresholds and those that may in the future. Vulnerability is a dynamic and broad concept designed to identify not only poor households, or who may otherwise be vulnerable, but also members of the family who are experiencing the greatest weaknesses, such as children, the elderly, disabled people, teenage mothers and female heads of households. For the identification of vulnerable groups and families, the government uses the *Registro Social de Hogares* (Social Household Registry) an instrument that supports the application and selection of beneficiaries of the State's institutions and agencies that provide social benefits.[39]

Elderly care and the elderly, as a specific vulnerable group, have slowly entered into the government agenda, with important advances in the past decade. The creation of the *Servicio Nacional del Adulto Mayor* (National Service of the Elderly, SENAMA) and more recently, the

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[38] Since 2015, the notion of poverty has been expanded and to consider "multidimensional poverty" that includes not only monetary income but seven other dimensions relevant to the wellbeing of households and their members. These non-monetary income dimensions are: education, health, work and social security, housing and environment, networks and social cohesion.

[39] The Social Household Registry is a large database containing information from households, based on administrative data held by the State and data declared by households. The database combines information from institutions such as the National Civil Registry, the Internal Revenue Service, the Pension Superintendence, the Health Superintendence, the Public Health Insurance system and the Chilean Registry of Schools, among others.

announcement of the creation of a National Subsystem of Care and Support are key developments. However, challenges remain for elderly care to receive the attention and priority it deserves in public policy.

This chapter covers part of the macro dimension of elderly care, seeking to understand the evolution and status of the State's role in elderly care. It frames the government's role by characterising Chile as a care regime, and analyses the specific policies available to support elderly care. The chapter first discusses the Latin American welfare regimes typologies to then situate Chile into a welfare typology and understand the social distribution of the elderly care in Chile and the government's role in providing welfare – and consequently, in providing or supporting elderly care. The third section of the chapter analyses the more specific role of the State. It refers to the historical development of the Chilean elderly care policies and their main features; all in the general framework of Chile's social policies.

The chapter acknowledges the important steps that the Chilean government has taken towards adopting a more active role in elderly care. Despite these advances, the analyses recognise there is more to be done. The chapter's last section refers to the barriers and challenges the Chilean government faces to adopt a more active and meaningful role in elderly care.

The first three sections of the chapter draw from a literature review; the fourth section draws from both a literature review and interviews with key informants working directly or indirectly with elderly care at the local and national level. These key informants are geriatricians, health professionals working in the primary health centres, municipalities, and community centres and associations as well as experts and officials working in issues related to elderly care in the policy area or at a national level. Key informants thus come mainly from government agencies, universities and private care service providers. Together, key informants represent 14 different organisations. Chapter 2 provides more details on the key informants.

4.1 Welfare regime typologies in a Latin American context

The political and academic debate on the welfare system and social care is an emerging topic in Latin America and Chile (Acosta 2009). Filgueira (1998) makes one of the first attempts to classify Latin American welfare regimes. He argues that none of the conditions that allowed the emergence of the European welfare regimes are present in Latin America. The Esping-Andersen typology is unable to classify Latin American welfare states. The concept of a welfare state itself does not apply in Latin America because there is no social policy system that can be considered a welfare state. The current Latin American states social security structures do not guarantee minimum levels of security and equality.[40] For this reason, Filgueira (2005) refers to

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[40] Although there are similarities between Chile and the Southern European countries in terms of their welfare regimes, the general development of social protection policies is far more advanced in southern

the system of social policies and social protection as Social States which comprise the set of transfers, subsidies and services that resemble a social safety net and the set of redistributive transfers and services.

Martínez (2007, 2008) highlights that Latin American welfare regimes share common features: under the light of inefficient labour markets and weak or non-existent public policy, the family plays a key role in the provision of welfare, with a particularly relevant role played by domestic work and women in taking over caregiving tasks.[41] Three welfare regime types emerge the region after considering the family's and the State's risk management role: the *state-productivist regime* (e.g. Argentina and Chile), the *state-protectionist regime* (e.g. Brazil, Costa Rica, Mexico, Panama, and Uruguay) and the *familialist regime* (e.g. all the other Latin American countries). In both the state-productivist and state-protectionist regimes informal arrangements interact with public policy that either emphasises focalised policy (productivist) or more universal yet stratified social protection (protectionist). In the familialist regime the population relies largely on family arrangements, as social policies are non-existent or inadequate at best. In Latin America, access to paid work cannot be taken from granted in understanding the distribution of welfare so this typology introduces the *commodification* dimension and addresses the interactions between commodification, de-commodification, and de–familialisation. Commodification thus refers to how successful are labour markets in absorbing the labour force and paying for it appropriately.

Even though there are differences among Latin American countries regarding their welfare regime, they all show limitations in terms of the commodification of the labour force and the

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European countries than in Latin American countries. This is also the case for care and, specifically, for elderly care policies. It is also the case in Latin American countries that have been increasing their social protection role and their responsibility towards elderly care (e.g. Uruguay). Thus, although both Southern European and Latin American countries are considered to be *familialistic*, the scale of their familialism is not comparable or strongly differed.

[41] There are some efforts to categorise the emerging provision of social security in Latin America. Barrientos (2004), for example, argues that in the last two decades, Latin America has shifted from a *conservative-informal* to a *liberal-informal* social protection system. The conservative-informal type shares many traits with Esping-Andersen's corporate-conservative welfare regime. However, Barrientos's analysis is limited by the assumption that all Latin American countries follow a single system with no account for cross-country variability within the region (Martínez 2008). Rudra (2005) classifies the Latin American welfare policy orientation according to whether their public policies predominantly promote access to the market (*productivist regime*) or predominantly protect people from the market (*protectionist regime*). CEPAL (2010) classifies Latin American countries according to their *welfare gaps*. It analyses the scope of their social protection policies, their labour market features and characteristics of the family and demographic structures. Under this typology, one group of countries has wide welfare gaps: they have a reduced ability for public spending, large labour market informality, a relatively young population and a high poverty rate (e.g Bolivia, Ecuador and El Salvador). Another group of countries show narrower welfare gaps, together with an aging population and greater formality of labour markets (e.g Chile, Costa Rica and Uruguay). Another group of countries are somewhere between these two extremes (e.g. Colombia, Mexico and Venezuela).

regime's ability to de-commodify social risks. When contrasted against European welfare regimes, all Latin American countries are, to some extent, *informal*, in that a large proportion of the population cannot reasonably expect to cope with social risks by accessing services from the State or by paying for services available in the market (Martínez 2008). In general, and in spite of differences in coverage and public policy, social protection in Latin America relies heavily on family relationships and the provision of care lies most frequently on female unpaid labour than on public policy (Martinez 2008).

As primarily *familalistic* regimes, Latin American governments do not free families and women of caring responsibilities. Women's increasing participation in the labour market and the changes in the structure of the family have taken place without the State creating the conditions for the unfolding of this process though public policies. The State has also been practically absent in developing policies to de-familiarise welfare regimes. Families still take over most welfare functions (Sunkel 2006). The family's role in social protection lies mostly in providing for caregiving tasks within the context of family relationships; the role of families is also common in reaching out to garner the resources or services necessary for protection.

4.2 Chile's welfare regime

Chile is a regime characterised by the private provision of services, particularly in health, education and pensions, with a strong presence of informal protection mechanisms which include the family and social networks (Arriagada 2009). The State's role in welfare is one of support, not one of direct intervention. Based on the principle of subsidiarity, Chile's regime relies on a systematic dependence on family caregiving. Consequently, the family is encouraged to play their role through State support rather than be substituted through direct interventions. Though important advances have been made in the past three decades, the commodification of services typical of a state productivist regime has not been effective in meeting the growing demands for care among Chilean families (Acosta 2013).

The characteristics of the social organisation of care in Chile show how the welfare regime has shifted from a model of maximum private responsibility in the 1980s to one closer to the state productivist regime. The State adopts a role functional to market demands, compensating and correcting market failures. The family, and particularly women, still bear most of the care work. Women's care work, especially elderly care role, is not recognised at the public level. Recent reform processes have not corrected the exclusionary nature of Chile's welfare system as it remains focused on attending the needs of certain groups. The population left out of these benefits must resolve their care needs privately, usually relying on the less expensive and more functional alternatives for care from the perspective of the needs of the family and the care recipient. For those eligible, transfers and programmes are generally not enough to free the family and women of care responsibilities. Despite the efforts and notable advances, the family remains the principal welfare provider in Chile (Acosta 2013).

When comparing Chile to other Latin American countries, Martínez (2008) considers Chile's welfare regime as a *state productivist*, one where the state has begun taking a more important role in ensuring against social risks. This role, however, is only to compensate for the market's shortcomings as social protection still relies heavily on the private domain as a way to ensure welfare (Acosta 2013, Martínez 2008). The State plays a relevant role among groups experiencing the highest vulnerability; the State is practically absent for the rest of the population. The family and the market are the main and sole welfare provider for the majority of the population who does not experience vulnerability.

The state productivist regime acts through with a logic of focalisation (directed policies). Despite the recent trends towards rights-based universal social protection, focalisation based on the right to minimum conditions remains the current underlying logic in Chile's social protection system. One programme that exemplifies this logic is *Chile Solidario*, the anti-poverty programme introduced in 2002 as part of a wider drive to eradicate extreme poverty. *Chile Solidario* is a management model to articulate the main areas of social policy (health, education and financial security). It consolidates in one framework a network of subsidies, grants and non-contributory bonds, new and existing.[42] [43] It also offers services directed to

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[42] The benefits in *Chile Solidario* include:

- Single Family Subsidy (*Subsidio Único Familiar*): a monthly subsidy of 6,500 pesos per month (around 9 euros) readjusted yearly payable for each person under 18 years of age, disabled person of any age, mothers of children who live at their expense and pregnant women in the household.
- Mental Disability Subsidy: grants 52,730 pesos per month (around 75 euros) to people over 18 years old from low-income households who have been declared mentally disabled by the Commission of Preventive Medicine and Disability.
- Identity card allowance, which subsidises the value of the identity card to all those who belong to *Chile Solidario* programme.
- Subsidy for the payment of potable water and sewage wastewater: covers 100% of monthly consumption of up to 15 cubic meters of water for those who reside permanently in a home with connection to drinking water.
- Preferential subsidy and pro-school retention: delivered directly to holders of educational institutions to achieve recruitment and retention of children and youth participating in *Chile Solidario*. The subsidy varies between 61,109 pesos and 146,657 (around 90 euros and 210 euros, respectively).
- Basic solidarity pension: a direct monthly allowance to people over 65, created within the framework of the 2008 Pension Reform.

In addition to the bonuses and subsidies, *Chile Solidario* generates a series of agreements with public organisations so that they ensure priority access for its beneficiaries to their programmes and, in several cases, generate a specific offer for this group. Thus, it is possible to identify programmes in the areas of health, education, employment, housing and justice that the beneficiaries of *Chile Solidario* can easily access.

[43] In addition to the innovations implemented for all people living in poverty and extreme poverty, the Chilean social protection system also includes specific actions to the most vulnerable age and occupational groups. Although they primarily target the population living in extreme poverty, they are

families in extreme poverty and coordinated by the Ministry of Social Development. Technical responsibility lies in this Ministry, which manages the financial resources, coordinates the network of participating institutions, monitors progress and evaluates outcomes. Municipalities are the point of contact between families in extreme poverty and the programme. Municipalities are in charge of implementing the various facets of the programme. The municipality has family supporters to form local intervention networks. They are representatives from all institutions and public and private organisations that provide services to participating families. Families' specific needs are considered in the programme, which has the flexibility to direct specific resources when users' needs are not covered by the regular programme.

Chile Solidario, one of the most important pillars the social protection system, acts to offer support to those who cannot access the market, that is, families in extreme social vulnerability. The State acts to protect individuals who live in families without the means to buy protection.

Though significant changes have been implemented in the regulatory bodies governing social protection in general, policy development to support care for elderly dependents has been weak at best.[44] Few, if any policies recognise elderly caregivers' rights. The right to care and be cared is not explicit in any legal instrument; they are only implicitly mentioned in some legal instruments, hindering their recognition, management and enforcement (Guzmán y Huenchuán 2005). Furthermore, there are contradictory positions between the government's political discourse and the legislation's potential effects. For example, the political discourse recognises a social-rights approach and strengthening of citizenship in the provision of social goods and services, but in practice this applies only to a logic of 'minimum conditions to guaranteed quality of life' (Acosta 2015, 2013).

The Chilean model of care corresponds to a model of private care, with public support and help. This model is based on a systematic dependence on the family, with support offered to the family based on the principles of subsidiarity. The family is encouraged to play their caregiving

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built from a more comprehensive view of social protection and rights for all citizens. They show, a wider criteria for inclusion and coverage levels than those of *Chile Solidario*, combining the delivery of cash transfers (e.g. the Basic Solidarity Pension) with other benefits that seek to promote lifelong access to social services. Example include the intersectorial system for infant protection *Chile Crece Contigo,* the pension system based on individual contributions and the unemployment insurance scheme.

[44] The support for childcare is quite different when compared to elderly care. In terms of childcare, the government has implemented a comprehensive protection system for early childhood, *Chile Crece Contigo* (Chile Grows with You). This system guarantees children's access to childcare and early childhood education, health check-ups and support, offers pre-natal and parenting support. The majority of the policy measures included in this programme have universal coverage that includes all children under the age of four and their mothers who are in the public health system. In addition, the programme offers additional subsidies and support for families with children and a household income below the 60th percentile of the national household income distribution. Chile Grows with You's budget doubles that of the entire SENAMA.

role through state support; no direct interventions replace the family in caregiving (Acosta 2013). Though it may be the case in childcare support that Chile may be transitioning from an implicit *familialism by default* to a *supported familialism* care regime, when considering elderly care and despite advances made (especially in the recognition of the importance of this topic), Chile remains an *unsupported familialism* care regime.

Chile, as well as some other Latin American countries, seeks to provide some care services (especially childcare) via employer mandates on large businesses. Such mandates transfer care responsibilities from the mother to the employer during the workday. These mandates are established only for women and on the basis of the number of women employed. They reinforce the idea that caregiving is solely a female responsibility. It can also increase employers' propensity to discriminate against women in hiring decisions. As such, these policies may actually aggravate the gender gap in the labour force by encouraging employer discrimination against women. They also exclude the large share of women in informal work or in small firms. Theoretically, mandated employment-based care could encourage use by fathers but no such cases exist in Latin America (Blofield and Martínez 2015).

The following sections first review the historical development of the welfare state in Chile and then describe the existing government policies and recent trends to support elderly care. The many initiatives highlighted in the section may come as a contradiction to the general conclusion of this study that the government's role in elderly care is minimal and progress is slow. While the many initiatives signal an undeniable movement towards the recognition of elderly care, it ought to be put in the context of the very low coverage of the programmes, slow speed of their development and the challenges that still hinder public support for elderly care. The final section draws on the previous analysis and the interviews with key informants to understand how and why, despite advances made, the bulk of the responsibility for elderly care still relies on the family.

4.2.1 The historical development of the welfare state in Chile

Chile's current social organisation of care, and the specific role of the government in the elderly care, is better understood in the context of the country's political and institutional development. Three periods characterise this development: a) a developmental state at the beginning of the XXth century, b) a neoliberal regime during the military government of the 1970s and 1980s and a c) the post-neoliberal state of mixed policies from the 1990s onwards (Arriagada 2009).

Social protection policies reinforced women's role as caregivers in the domestic arena in both the developmental State and neoliberal regime. Although women were not completely ignored in public policy – policies to remove barriers for the access into public life were implemented – little, if anything, was done to remove barriers in private life (Provoste 2012).

Developmental state

Prior to the developmental state period, social protection in Chile and Latin America was characterised by the State's absence in the social sphere. Prior to the XX^th^ century, the government's role was focused on the formation of the State, the establishment of national borders, building the infrastructure for trade and transport and safeguarding internal order (Larrañaga 2010). In Chile as in the rest of Latin America, the development of social protection systems in the early decades of the XX^th^ century was a response to workers' increasing demands for ensuring labour rights and better living conditions. The developmental state brought a series of housing, employment, health and education initiatives.

The system emerging at the beginning of the XX^th^ century was based on universality, solidarity and comprehensive social security. It had a redistributive and compensatory function (Sunkel 2007). In this model, access to rights was linked to formal employment, meaning that the target for social policies were formal workers and their families. Informal workers remained out of coverage as the premise was that universal coverage would be attained through formal work. This model for access to social rights is based on a traditional conception of a family headed by a male formal employee and a dependant wife and children, all of whom benefited from health care, housing, retirement, holidays and other benefits through the formally employed adult man (Provoste 2012). The welfare regimes in this period privileged the breadwinner model in which the family, and particularly the woman, was responsible for care while adult men played the role of financial provider for the rest of the family through formal employment (Del Valle 2011).

Neo liberal regime during the military government

The period between 1973 and 1989 is characterised by political authoritarism and economic neoliberalism. The military coup marked a profound break in Chile's political and institutional history. It shocked social life and weakened the links, trust and reference groups. Parliament was dissolved, political parties, unions and social organisations were banned, discussion spaces and democratic participation were closed and human rights were systematically violated. The package of inclusive reforms that recognised the citizenship of previously excluded social sectors was dismantled (Arriagada y Todaro 2012).

The military government changed the previous orientation towards universal access and rights via formal employment. The prevailing liberal macroeconomic thinking that guided policy-making in this period drove a reduction in the State's role to allow market forces to operate freely (Provoste 2012). Consistent with the principle of subsidiarity, public policies transferred decisions, responsibilities and social protection institutions to the market and private sector provision (Racynski 1994).

The neoliberal economic model was organised around three main areas: strengthening and expansion of private property while reducing the State's role in the economy to subsidiarity; strengthening the free market and the indiscriminate opening of most, if not all, products and services to foreign competition and foreign investment; and the redefinition of the form and shape of the economic model to achieve economic growth (Arriagada y Todaro 2012).

Chile's social policy underwent a major restructuration during the military government involving i) focalised policies and direct monetary transfers, ii) decentralisation and iii) marketisation of services.

i) Focalised policies and direct monetary transfers

The military government designed a network of direct subsidies to people in extreme poverty, which remains today (Racynski 2008). The principles of directing subsidies to the poorest made the provision of services and benefits independent of employment status and conditional on a situation of extreme poverty. Cash transfers to individuals are a traditional social policy tool in Latin America.[45] In the developmental stage, subsidies are delivered as housing and family allowances, which are understood as rights related to wage emplyoment. In expanding the neoliberal model and the notion of focalization, social support evolved to subsidies and assistance to the poorest. Most subsidies comprise small monetary transfers. Family allowance is reduced to the minimum, and several formulas were created to verify requirements and implement their delivery, so to focus on those who need them the most (Provoste 2012). In general, these monetary transfers sought to increase the income of the lowest income households directly, reducing the general poverty levels of the country and facilitating the poor's access to the market. These subsidies are based on the principle of aid, not that of a right. In this model, access to State aid is based on need, not on citizenship (Pautasi 2007).

This scheme reinforces or reinvents the role of women as direct articulators between the State and the family. This period highlights women's role as mothers, less so of a wife as in the previous developmental state. Both the developmental state and the neoliberal regime, however, take women's place in the home space for granted (Provoste 2003).

ii) Decentralisation

The implementation and management of social programmes was transferred to the private sector and from the central government to a sub-national level (municipalities). The administration of primary health centres and basic and secondary education centres, as well as the implementation of focalised and compensatory social programmes was transferred to municipalities. Market

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[45] Other countries (e.g. Brazil) have also readjusted the conception and scope of their social policy to the changes in development models and have adopted cash transfers as an important tool for the delivery of social policy.

mechanisms and economic incentives were introduced to, in principle, encourage better performance of services (e.g. demand-side subsidies, education vouchers, billing for health care provided) at the local level. This transfer of management and introduction of incentives was imposed with no consideration of municipal authorities and officials' capacity to cary out these new tasks. In addition, health services staff and teachers lost their labour rights, their collective bargaining power and saw their salaries drop. Public social expenditure strongly decreased and became concentrated on direct monetary subsidies to the most economically vulnerable population through directed policies (Racysnski 1994).

For Coraggio (1991), a process of decentralisation can take two distinct emphases. On the one hand, decentralisation can emphasise the free market at the local level; the idea being that potential providers choose according to local comparative advantages and needs to become or not services providers. The State's role is to guarantee good market functioning. On the other hand, decentralisation can emphasise the local initiative of local actors who lose identities and protagonism in a globalised system. This form of decentralisation legitimises action through a more democratic process and an underlying project of humanising society. Chile's decentralisation process carried out during the neoliberal period of the Chilean government corresponds to the first type, by focusing on the liberalisation of the service markets at the local levels, reducing the social functions of the State. As part of the military regime's reform, Chile's decentralisation process was marked by a transfer of functions, and a complete absence of any democratic element. The transformations and measures taken in this period are still today the basis of the decentralised institutional system, discussed later.

iii) Marketisation

The education, health, housing and social security systems were reformed to give a greater role to the private sector and the market. In health, the private health insurance institutions (*Instituciones de Salud Previsional,* ISAPREs) were created and the social security pensions system changed to a privately administered individual capitalisation system (*Administradoras de Fondos de Pensiones,* AFPs). The possibility to deposit health insurance payments and retirement savings on private firms and the option of free choice of providers channelled of a substantial part of the demand towards private providers, promoting the creation of an industry that would experience big growth in the following decades. The logic of private health insurance led to a segmentation of the population according to risk, since insurance plans are individually based. Plans for the elderly and women of childbearing age are more expensive as they have higher expected health spending. Given their higher premiums, they tend to join the public health insurance system (Larrañaga 2010).

One of the main expected outcomes of the free market regime was that people could afford their own health care costs and retirement, freeing the State of this burden. More generally, the free market was expected to improve the level and quality of employment, improving, indirectly health care and retirement prospects for individuals. The free market did not fully dismantle the State and failed to improve full or a better employment prospects. The new system also failed to ensure decent retirement pensions. This paradigm of free market is not fully implemented in any other Latin American country; governments maintain to a higher or lesser extent their role in social protection. In Chile, the government's sponsorship of market's role in social protection during this period was strong and explicit (Provoste 2012).

This shift brought about by neoliberal policies entailed significant changes in the relationship between gender and social protection. The increased labour market flexibility and the consequent rise of precarious employment affected women the most. On the one hand, women often entered the labour market through precarious jobs, restricting their access to social rights through their insufficient earning. This is coupled with the disadvantage that resulted for women the dismantling of the male breadwinner model in the organisation of social protection (Provoste 2012). The neoliberal regime resulted in a growing commodification of welfare, which decreased the likelihood that a significant part of the population could effectively access to welfare (Martinez 2007).

Post-neoliberalism

From the return to democracy in the early 1990s to the present, social policy has been creating institutions to support the protection of vulnerable groups. The first efforts were directed to households living in poverty and has gradually extended to other vulnerable groups (such as young children, rural populations, women and, recently, the disabled and the elderly) and programmes directed at correcting market failures and enhancing directed policies (e.g. by increasing coverage of eligible individuals, increasing the number and amount of subsidies available). This entailed a change in the neoliberal-inspired social policy towards a new and more complex social agenda that addressed population groups and individuals with specific needs. The 1990s, brought the creation of many specialised agencies and the development of programmes operated within those agencies, focusing on the urban and rural poor, women, farmers, indigenous people, youth, elderly and the disabled (Racysnki 2005).

Between 1990 and 2000, emphasis was placed on reducing poverty. Budget for health and education increased and specific programmes directed to the more vulnerable population were implemented. From the year 2000 on, the emphasis moved to the gradual installation of a Social

Protection System covering vulnerable populations beyond those in extreme poverty.[46] By the 2000s, public policy discussion began to shift to a perspective of rights, though the current arrangement has yet to reach a full exercise of rights (Acosta 2013).

Especially during President Bachelet's first government (2006-2010), greater emphasis was placed on what has been called a Social Protection System Based on Rights, guaranteeing access to certain social protection schemes. The Social Protection System Based on Rights includes several initiatives to guarantee the financial security and the access and quality of education and health with an emphasis on the more vulnerable population groups: the elderly, housewives, children under six years old and the poorest population. Important reforms related to the social provision of care are developed, including the reform to the pension system which added a solidarity pillar to the individual capitalisation system so that all pensioners would have access to a basic solidarity pension of 93,543 pesos (approximately 135 euros); a reform to the health system and the creation of the *Garantías Explícitas en Salud* (Health Explicit Guarantees, GES), which guarantees health care access and coverage of 80 pathologies; and the *Programa Chile Crece Contigo* (Chile Grows with You) which guarantees children's access to childcare and early childhood education, health check-ups and support, offers pre-natal and parenting support, as well as additional subsidies and support for families with children and a household income below the 60th percentile. This social protection system conceptualized from a rights perspective guaranteed the gradual access of the population to social and economic rights that accompany people from birth to old age; it has meant that little by little, the Chilean State has increased its role in ensuring social protection (Arriagada 2009, Robles 2012).

Despite the current trend towards a rights-based social protection system, the welfare state that has developed since the 1990s has a clear liberal take and is similar in orientation to that in the United States (Tironi 2005). The principle of marketisation continues to operate (e.g. in health and education provision and despite current attempts towards reform). Private entities and organisations act as collaborators of the State in the implementation of social programmes: for profit organisations, consultants, NGOs or foundations, universities, are usually in charge of delivering and providing social goods and services. Public procurement through *Chile Compra* (Chile Buys) is the mechanism by which State selects, hires and transfers resources to service providers (Raczynski and Serrano 2005).

The two decades spanning 1990s to the 2010s were marked by the gradual consolidation of the social protection system in Chile, as is the case with public policy in general in the country. The Chilean social protection system developed as a sequence of intensive reforms and innovations

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[46] A Social Protection System is an integrated and specific system of norms, mechanisms and institutional units that ensure the provision of social services, according to the financial resources and allocation criteria defined by law (MIDESO 2015).

that have been incorporated into the various social policy areas. These include long-term processes aimed at permanently reforming institutions (e.g. adding a rights-based orientation to social protection to vulnerable groups, health and education and moving away from contributory schemes) and transitional measures to protect against specific emergency situations or risks. The concept of social protection that has developed is broad with an important role played by public institutions. Social protection is increasingly – though not definitively – built from a perspective of citizenship, oriented to protecting the entire population and throughout the life cycle. A rights-based approach anchored in human rights has resulted in innovative designs, particularly in the fields of health and pensions (Robles 2012). Chile is one of the pioneering countries in the region in expanding health services and free basic education, developing specialized public bodies and social services in these areas. To illustrate, Chile showed a dramatic decrease in infant mortality rates, the result of maternal and child health policies promoted from the second half of the last century (Jimenez de la Jara 2001), and a sustained progress in the enrolment and coverage of educational establishments.

From the perspective of management and social information, an intersectorial social protection system has been developing during the last two decades. Fiscal sustainability has also been carefully considered in the design and implementation of the system of social protection and promotion as a whole.

The institution coordinating social policy, including social protection, is the Ministry of Social Development (MIDESO), created in 1990.[47] Its objectives include the promotion of national development and social policy actions. This includes both the analysis, design, coordination, implementation and evaluation of social policies, plans and programmes; the proposition of public investment goals and evaluating their initiatives; and the generation of information and analysis on the social and economic reality. MIDESO strengthened the practices and structures of intersectorial coordination and improved the availability of information and indicators regarding the needs of the population.

Despite the important efforts made to strengthen the social protection system, the main features of the reforms implemented during the military regime still remain in the current social protection system. They include: i) the continuation and extension of focalisation principle, ii) a decentralised implementation within a centralised structure, and iii) a predominant role for the market with implications for those who can’t access.

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[47] Originally, the Ministry of Social Development was called *Ministerio de Planificación y Coordinación,* Ministry of Planning and Coordination

i) The continuation and extension of the focalisation principle

The principle of focalisation continues as the main guiding principle in Chilean social policy. The logic of focalisation that developed since 1990s is larger in coverage and transfers compared to that initiated during the military government. The addition of new monetary transfers reflects the limits of initial programmes in ensuring or promoting independent income generation by the families that receive those transfers (Robles 2012). Today, monetary transfers have important effects on the reduction of extreme poverty and income inequalities. For example, Chile's Gini coefficient of income inequality[48] without considering the monetary transfers is equal to 51.3, while it equals 43.4 after considering all monetary transfers (Larrañaga y Rodríguez 2014).

Since the 1990s, the focalisation principle has been extended beyond just socioeconomic vulnerability criteria or specific demand. The current criteria for focalisation varies across programmes; in some cases provision is to individuals depending on their socioeconomic characteristics (e.g. *Bono Marzo*, a subsidy of around 60 euros paid in March each year to eligible families), in others it is based on selected geographical units deemed at disadvantage (e.g. *Subsidio a la Calefacción,* a subsidy to help households cover heating expenses in colder areas); in others it corrects for market failures (e.g. in cases where private school providers do not enter a specific locality). Focalisation is still very much present, but the criteria and mechanisms applied vary according to the objectives pursued by the programmes (Raczynski and Serrano 2005).

Focalised social spending has also been reinforced through the expansion of conditional cash transfers, one of the most widespread government social protection tools in Chile and Latin America (Sojo 2007) (e.g. *Bono Logro Escolar,* a subsidy of around 80 euros to families in the lower 30th percentile of the income distribution whose children are among their cohorts' highest achieving 15%; *Bono Control de Niño Sano al Día,* a 10 euro subsidy granted to disadvantaged families who keep their children's health check-ups up to date).

The myriad of subsidies and focalised programmes available show the institutional strength and political capacity to incorporate policies to overcome social and financial risks. They reflect the broader approach to social protection policies. However, social policy largely based on the expansion of this type of programmes maintains and strengthens women's role as an articulator between the family and the State, as they are, in most cases, in charge of registering (if needed)

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[48] The Gini coefficient is a measure of a country's income inequality with 0 representing perfect equality (all residents receive an equal share of the country's income) and 100 representing perfect inequality (one individual receives the totality of the country's income). It is sometimes also expressed as ranging from 0 to 1.

and carrying the transfer to their homes. The purpose of redistribution of care between men and women and between different actors of the social welfare system is still far from the mainstream of public policy. Similarly the implications for care and the gender-biased distribution of care is never discussed in the design of any social protection programme (Provoste 2012).

ii) Decentralised implementation within a centralised structure

Decentralisation within a strongly centralised structure is another key feature of Chile's current governance model and a legacy of the neoliberal reforms of the 1980s. Following the transition to democracy, decentralisation has developed with periodical adaptation of the legal frame and a sustainable development of the resources assigned to local governments, making Chile a notable example in the Latin American context. However, Chile still maintains a highly centralised institutional and financial structure when compared to the countries of the region (Marcel 2008).

There is a consensus that Chile's return to democracy allowed for a better development of the process of decentralisation. Decentralisation as designed in the military regime has been adapted since the 1990s under the key concepts of autonomy, change in the structure of the State and participation.[49] However, the process is not yet fully developed and challenges remain, especially in ensuring a balanced and equitable local development and the modernisation of decentralised public management.

Decentralisation with centralised institutional and financial structure means that the social protection system is defined at the central level and implemented at the local level by municipal authorities. Resources, design and technical directions are centrally defined and translate into action through social programmes implemented by municipalities. Though in principle municipalities run public policies, the fact that design, resource allocation and technical direction are centralised, Chile has, in fact, a very centralized administration with little autonomy at the local level. Social policy in Chile corresponds to a model of *operational decentralization* (Raczynski and Serrano 2005).[50]

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[49] According to the World Bank (2001), successful decentralisation is closely related to observing the design principles of: informed decision making; adherence to local priorities; finance following; [clear assignment of] functions; and accountability. However, applying these principles is not simple. Country circumstances differ and the policy and institutional instruments that shape decentralisation have to be designed to meet to the specific conditions of individual countries.

[50] Chile's territorial and administrative division follows the concept of a Unitarian State, where political power and political functions are under one constitutional, legislative and judicial system. Chile is divided into 15 regions spanning north to south. Regions differ in terms of culture, economic activity, geography, climate, etc. Regions also have important socioeconomic and cultural characteristics within. Regions are divided into provinces, and provinces are divided into municipalities. Socioeconomically and culturally, municipalities tend to be more homogeneous. There are 54 provinces and 346 municipalities. Regional governors and provincial governors are appointed by the President. Mayors and municipal counsellors are elected to four-year terms.

Municipalities in Chile are very unequal in terms of their resources and services because a large part of their funding comes from local taxes such as property taxes and Chile has high levels of residential inequality (OECD 2015b). This financial model restricts municipalities' autonomy to develop their own programmes based on their own specific social needs as this local tax base is usually not enough to cover municipalities' basic needs, with the exception of a small number of municipalities that concentrate the country's high earning households. The *Fondo Común* (Municipal Common Fund) redistributes resources from richer to poorer municipalities, but is still not enough to break the strong inequalities in municipal revenues. An alternative form of municipal revenue is through central State-level programmes. Resources earmarked for the implementation of specific programmes' are channelled to municipalities through co-financing agreements. Though it increases available resources and contributes to turning municipalities' attention to social issues, resources are tied to specific purposes leaving little autonomy for municipalities to cater to their populations' specific needs (Raczynski and Serrano 2005).

iii) A predominant role for the market presence and implications for families without access

The market's role in the provision of social goods and services is another remnant of the neoliberal policy direction of the 1980s. It is expected that at least part of the population purchases health services, education and retirement pensions. Interventions and reforms in this area since the 1990s have maintained the market's role in the provision of protection. Most interventions have improved regulation and corrected market failures. Despite the efforts to expand the State's role (Robles 2012) and the move towards rights-based guarantees, the reliance on the market has meant that the family has had to take charge of protecting those who fail to integrate into the market or those who fail to hold a stable position in it (Tironi, Valenzuela and Scully 2006).

4.3 The role of the State: Institutions, policies and programmes for elderly people and for their care

The previous sections showed how the government acts where families cannot access welfare in the market or by themselves. Given the type of role played by the government and the focalisation principle, the family, and especially women, still play a pivotal role in welfare production in Chile, particularly in providing care for dependent elderly people. Previous sections also showed that in the Latin American context, Chile is, alongside Costa Rica and Uruguay, among the countries with narrower welfare gaps in the region and has an aging population.

This section explores the actions the government has taken to support the elderly and elderly care. It shows how the broader orientation towards social policy is expressed in the specific context of elderly care. Despite the weakness of the government's role and the consecutive strong reliance on the family to provide elderly care, there is movement in public policy to support elderly care. The Chilean government has begun to recognize the need to take an active role in the social protection of the elderly population. As discussed below, policies have slowly begun to consider care as a socially distributed responsibility and not only an exclusively family matter. Coverage remains, however, strictly limited and families remain as the main pillars of the provision of elderly care.

Prior to the 1990s, care for the elderly relied solely on the individuals themselves, their families and charitable institutions (Marín et al 2004). The rapid and recent growth of the share of the elderly population brought about a rethinking and extension of the initiatives taken by the State to ensure their welfare.

In Chile between 1920 and 1940, the population aged 60 years or older did not exceed 3.5% of the total population. By the 1970s this share had increased to almost 6%; by the 1990s it reached 10% (INE 2008). During the military government period (1970s and 1980s), the population aged 60 years or over was not subject to any focalised social programme. Some of the sectorial measures and social programmes that were launched in that period had a larger effects on this group (e.g. the creation of the private administration of pension and health insurance, for example).

Rather than adopting a development model that acknowledged aging, the prevailing development model in the neoliberal period sought to turn Chile into a more economically competitive country in a scenario of modernisation and neoliberalism. In this scenario, any social measure implemented during the time responded to a logic of assistencialism (Caro 2014). One exception throughout this period is the formation of the *Consejo Nacional de Protección a la Ancianidad* (National Council for the Protection of the Elderly, CONAPRAN), in 1974. Rather than a State-sponsored programme to support elderly care, CONAPRAN organised a network of female volunteers who gave support to elderly people living in poverty (Morales 2000).[51]

The government's approach to the elderly shifted in the 1990s to a perspective of social integration, coinciding with the greater emphasis of social policy on a system of social protection based on rights. In this context, the presidency of President Aylwin designs, in 1993, the *Política Nacional de Envejecimiento y Vejez* (National Policy of Aging and Old Age). It marked the first instance in which the issue of aging and care was recognised as a social problem. The elderly entered the public agenda as one more "vulnerable group" meriting public

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[51] Today, CONAPRAN functions as a private non-profit corporation with a strong base of volunteer work. It coordinates, among others, 13 nursing homes and day centres for the elderly.

attention and recognising the elderly as priority individuals for social security cover (Caro 2014, Morales 2000). Despite the achievement in political recognition, the policy did not set up social programmes designed for or directed towards the elderly. It did not create appropriate methodologies to confront the problem, exposing the disregard that reigned over the reality of the elderly in Chile during that period (Caro 2014).

In 1995, President Frei creates the *Comisión Nacional para el Adutlo Mayor* (National Commission for the Elderly), an advisory body to the President on all matters related to elderly people. This commission advised on the formulation of policies, plans and programmes for the elderly. This commission installs aging and the elderly as a priority in the public agenda, becoming a focus of public policy (Caro 2014).

In the context of public policy guided by a principle of subsidiarity, policies sought to garner and allocate resources to develop a national policy, narrowing gaps in inequalities by supporting elderlies who could not meet their needs or who did not benefit from economic growth. The Commission becomes the lead actor and promoter of change, replacing the assistencialist orientation of the previous governments, and promoting and coordinating across the various sectors (e.g. health, pensions, social development, municipalities) in developing actions to improve the quality of life of the elderly.

The Commission's work lays the ground for the creation of the *Comité Nacional para el Adulto Mayor* (National Committee for the Elderly) with the objective of coordinating and articulating the National Policy for the Elderly (Caro 2014). Through the Committee, the State assumes a subsidiary role in favor of the elderly, and tries to overcome the predominantly assistentialist care approach that existed until then. The State set limits on their responsibility towards the elderly care, mentioning the family as the first instance of care with a relevant role to play by the community as well. For the State, the responsibility for the elderly ought to be carried out without separating them from its habitual environment (Acosta 2015).

These efforts led to the formation of the *Servicio Nacional del Adulto Mayor* (National Service for the Elderly, SENAMA) in 2002. SENAMA became, and still is, a functionally decentralised public service with legal personality, with its own patrimony. It is under the supervision of the President of the Republic through the Ministry of Social Development (MIDESO).

SENAMA's main objective is to achieve a cultural change that results in better treatment and higher valuation of the elderly in society, thus achieving better quality of life for all elderlies. Through this objective comes the recognition that the elderly concerns society as whole, not just public agencies involved. SENAMA's programmes are developed by considering *autonomy*, *active aging* and *full citizenship* as guiding principles; that is, self-reliance, inclusion and participation in economic, cultural, artistic and civic life, among other dimension of society (Caro 2014).

Chile has taken the important step of recognising the elderly as a group of social importance and recognising the government's responsibility towards this group. However, few efforts have been made to advance programmes and policies directed to elderly care needs and the needs of their caregivers. From the moment the elderly began to be part of the government's agenda, social policy towards this group concentrated on autonomous elderlies with the main objective of increasing their participation in societal life and delaying the onset of dependency (Albala et al 2007). The public offer of elderly care services follows the focalised principle of the Chilean social protection system. It focuses mostly on the most financially vulnerable population, so coverage remains specific to particular groups (Acosta 2009). The following sections provide an overview of the policies and programmes that benefit the elderly directly and those aimed at supporting the elderly care.

4.3.1 Elderly care: SENAMA's programmes

Various initiatives translate SENAMA's principles into concrete policies and programmes. The *Programa Vínculos* (Links Programme), executed jointly by MIDESO and SENAMA, aims to ensure that people aged 65 and over and in vulnerable situations count on guaranteed benefits, have preferential access to relevant social benefits and are integrated to the community network of social protection. The *Fondo Nacional del Adulto Mayor* (National Fund for the Elderly) funds selected independent projects in all regions of the country. The programme of innovative interventions for the elderly promotes innovation towards the local expertize and professionalization of municipals workers towards the benefits of the elderly. The *Derecho a Techo* (Right to a Roof) implemented by the Ministry of Housing (MINVU) and SENAMA, looks to improve the quality of vulnerable elderlies to promote their autonomy and independence. The programme *Asesores Seniors* (Senior Consultants) draws on elderly to provide out-of-school tutoring to vulnerable children in school age. The *Fono Mayor* (Elderly Phone) programme is a free communications service that provides information related to aging and aging services for all. SENAMA promotes training for elderly community leaders to develop elderly community organisations for the elderly. Finally, the *Turismo Social* (Social Tourism) programme encourages access and participation of the vulnerable elderly people to tourism and recreation (Arriagada 2009).

Elderly care programmes SENAMA has designed and currently implements include (SENAMA 2016):

- The *Programa Cuidados Domiciliarios* (Home Care Programme) was designed by SENAMA and begun implementation in 2013. It seeks to improve the quality of home care for the elderly by training community members to become caregivers and offer respite to family carers. Communal caregivers must be at least 18 years of age and have completed lower secondary education. They replace the family caregiver of the elderly once a week for two hours. They receive between 15 and 25 euros a month for every elderly they care for. Ideally, communal caregivers transmit the knowledge they gain in training to family caregivers. Each municipality or non-profit organisation that wants to implement this programme has to apply to SENAMA who offers the funding.

The programme's budget accounted for little less than 600,000 euros in 2016 and is used to cover operational costs and train caregivers. A monthly payment of 30 euros was paid to the executing agents on a pay-per-beneficiary basis. The number of caregivers and their working conditions (e.g how many beneficiaries each serves) are unknown at a central level. When the executing agencies were NGOs or faith-based institutions, they could rely on volunteer work, and volunteers were given a stipend (Matus-Lopez and Cid 2015).

Eligibility to this programme is limited to elderlies with moderate and severe dependency level, over 60 years old and who belong to a disadvantaged socioeconomic group. It is also restricted, by design, to inhabitants of municipalities that choose to implement the programme and to those elderlies that have a main caregiver. Some 1,700 Chilean elderlies participated in this programme in 2015, which means coverage of 3% of the potential population (Banco Integrado de Programas Sociales 2016a).[52]

A professional in charge of implementing the Home Care programme in an urban municipality in Santiago reports that one of the major limitations of the programme is the non-continuous funding offered and the time required to apply and receive the next year's funds. SENAMA only provides funding to run the programme nine months per year; the remaining three months are spent re-applying to receive the following year's funds. For participants, this design means they do not receive home visits for three months; during these three months the main family caregiver does not receive the two weekly hours of respite. According to the professional, failure to provide the programme continuously over the year stagnates or worsens the quality of care received by the elderly. Often, the worsening is irreversible (Key informant from the Home Care Programme in a municipality in Santiago).[53]

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[52] In Chile, there are 55,322 elderlies with moderate or severe dependency who qualify in the programme as they belong to the bottom 60% of the national index of economic and social status (Banco Integrado de Programas Sociales 2016a).

[53] Other, more general, limitations associated to this and other programmes are discussed in the last section of this chapter.

- *Establecimientos de Larga Estadía para el Adulto Mayor* (Elderly Residences for Long Term Care, ELEAM) started operating in 2007, it is the oldest of SENAMA's elderly care programmes. They are partly or completely financed and managed by SENAMA and supervised jointly by SENAMA and the Health Ministry. Following the same logic as the Home Care Programme, SENAMA delegates the management of elderly residencies to municipalities or non-profit organisations with experience in elderly care that apply to the available funding.

  As of 2016, SENAMA supervises thirteen ELEAMs, all built in a cooperation agreement between SENAMA and the Ministry of Housing and Urban Development (MINVU). MINVU builds the residencies and SENAMA manages; SENAMA operates service delivery in partnership with organisations with experience in elderly care provision. SENAMA pays for the residency's equipment and pays the managing institution a fee or monetary voucher for each elderly they receive (through a pay-per-beneficiary system). ELEAMs are managed by local governments, by faith-based institutions, by regional health services and NGOs. In 2014, the monthly amount paid per beneficiary was little less than 130 euros for slight to moderately dependent individuals and around 170 euros for severely dependent beneficiaries. Beneficiaries are expected to contribute through co-payments, which have a maximum limit of 85% of the dependent's pension. Each centre has a staff of 40 to 70 people, including managers, caregivers, administrators, and food and cleaning services. Caregivers are required to have completed secondary education and have attended a course of at least 6 months related to care for elderly people and/or sick people. The average monthly salary of a caregiver reached around 450 euros, around 60% of the national average salary (Matus-Lopez and Cid 2015).

  To be eligible to live in one of the residencies, elders must be older than 60 years, with a low, moderate or severe dependency level, living in social and economic vulnerability, with no effective family networks and support. Elderlies who have suffered from domestic violence are also eligible. Some 658 elderlies resided in ELEAMs in 2015; a coverage of 0.1% of the potential population.[54] In the case an ELEAM is available in the municipality, the eligible elderly usually have to wait at least a year to find a place in an ELEAM. A considerable amount of those in the waiting lists have died whilst waiting (Universidad San Sebastián and ACNexo 2012).

  Within SENAMA's 2015 budget by programme, ELEAMs constitute the second highest expenditure (Banco Integrado de Programas Sociales 2016b).

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[54] Some 660,765 elderlies are eligible for this type of residence (Banco Integrado de Programas Sociales 2016b).

- The *Fondo de Subsidio para ELEAMs* (Subsidy Fund for ELEAMs) started in 2013 and offers additional resources for public or non-profit private ELEAMS to improve the resident elderlies' living conditions. ELEAMs participate in a call for proposals with a project to develop at least one of the following aspects: basic needs satisfaction, specialised health care delivery, re-integration strategies for the elderly into the community, promotion of elderly rights and/or promotion of active aging. Being specific to ELEAMs, funded projects ultimately benefit elderly with moderate or severe dependency coming from disadvantaged socioeconomic households.

  This project received SENAMA's highest budget allocation in 2015, 6,337,544,000 Chilean pesos, equivalent to around nine million euros (Banco Integrado de Programas Sociales 2016c).

  - *Centros Diurnos para el Adulto Mayor* (Day Care Centres for the Elderly) began in 2013. Also referred to as *Centros de Día*, they welcome elderly with low dependency and a low level of depression during the day, allowing them to maintain their family and social environment when they return home in the evenings. Eligible elderlies must come from socioeconomically disadvantaged households and must live in the municipality where the centre is located. A multidisciplinary team deploys socio-sanitarian interventions such as therapeutic and rehabilitation activities, basic nursing, food, transportation, education and family training. As in other programmes, municipalities or non-profit private institutions operate the centres; SENAMA offers the funding and supervises them. There are 14 centres in operation, covering a small fraction of the 345 municipalities in the country. There is only one centre in the country dedicated to elderlies with cognitive dependency. This centre is financed with discretionary funds of the director of SENAMA, and it is located in a municipality of the Metropolitan region. In all, *Centros Diurnos*, cover 0.3% of the potential population.[55] The budget for the operational cost reached 1.2 million euros. The budget does not finance investment in infrastructure, payment to the executing agencies is through a pay-per-beneficiary system. A monthly voucher of around 95 euros is paid per participant. No out-of-pocket payments are allowed. There are no exact statistics regarding the number of people who work in the centers, nor about their working conditions. SENAMA only proposes a structure of socio-sAntoniary professionals and recommends that caregivers have technical studies (Matus-Lopez and Cid 2015).

In all, SENAMA's programmes reflect the recognition that there is a need to support the provision of elderly care and that the State should take an active role in meeting these care

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[55] Some 1,686 elderlies, over a total of 660,764 potential participants participate in the Day Care Centres (Banco Integrado de Programas Sociales 2016d). Eligible elders must come from the bottom 60% of the index of socioeconomic and social vulnerability (as measured by the *Ficha de Protección Social*).

needs. Such recognition is an important step and a political accomplishment. SENAMA has been gradually expanding its sphere of influence, either by encouraging the participation of elderly people, by their leadership in Latin America or by consolidating their working teams (Huenchuán 2016). Yet, there is still much room for improvement, particularly in terms of the elderly care. The population that can really access to these programmes is minimal in comparison to the population that is in need for these programmes. For example, only a 0.3% of the eligible population participate in Day Care Centres. This share is even lower if the population in need is expanded beyond the socioeconomically disadvantaged to consider all households who do not have the economic means to solve the elderly care in a different form than that of informal family care, usually in the form of a fully dedicated daughter or daughter-in-law. Furthermore, there is insufficient financing for the programmes; the pay-per-beneficiary system of the Home Care programme is less than 10% of the estimated cost for a formal home-based care system, which reaches around 3350 euros annually per elderly (Matus-Lopez and Cid 2014). Also, although there are no estimates for the cost of day care centers and elderly care residences, international evidence shows that these are also underfinanced (Genworth 2015 in Matus-Lopez 2015).

SENAMA programmes are primarily intended to improve the quality and conditions of the elderly care, and therefore they only consider the family caregiver from a technical perspective; caregivers are a tool towards achieving the goal of improving care. None of SENAMA’s programmes recognise carers’ social role and position. The programmes that offer respite to family caregivers offer the respite as a way to ensure a better quality of the elderly care, not because they recognise carers’ role. In fact, *Cuidados Domiciliarios* offers respite to increase the care quality under the assumption that an overloaded caregiver can lead to domestic violence which ought to be avoided. SENAMA’s objective is the population of elderlies, not caregivers (Banco Integrado de Programas Sociales 2016d, Key informant from SENAMA).

In general, care policies are distinct from other social policies such as health, education or financial security. However, social care policies are also directly connected with others; these linkages need to be considered when implementing care policies (in the dual role of providing and receiving care). Policies tend to work when care is transversal to the set of policies in place (Batthyány 2015). Social protection policies, financial protection policies, educational policies; health policy; housing policies, urban planning and transportation; policies regulating the labour market, among others are clearly linked to elderly care policies (Batthyány 2015). Governments that adopt a more active role in domains such as financial protection and health care, grant the elderly higher autonomy and alleviate their families for the provision of financial support (Saraceno and Keck 2010). The following sections review financial security policies, health care and social care policies related to elderly care.[56]

4.3.2 Financial security: Pensions

The Chilean government implemented a pension reform in 2008 to improve equity in access to the financial security component of social protection. By making individual contributions mandatory, adding the possibility of including voluntary pension savings and adding a solidarity component, the reform extended pension coverage to sectors previously excluded (e.g. independent workers or adults with no pensionable work experience), increased and offset the contribution density to increase pensions and reduce the final tax burden, formalised and consolidated the different forms of pensions savings, and reduced gender and social inequalities in social welfare (Robles 2012).

Following the reform, the pension system now combines elements of individual capitalisation with income redistribution. Though it adds a solidarity component, the reform does not modify the capitalisation system. However, the solidarity pensions represent a consolidation of the State's role in the pension system to protect the more vulnerable population against financial risks. Women and people with low educational attainment are those who have benefitted the most from the solidarity pension (Larrañaga 2010).

The solidarity pillar of the Chilean pension system is funded through taxes and operates through the following subsidies:

- The *Pensión Básica Solidaria* (Basic Solidarity Pension) is a monthly allowance given to the elderly from the lowest socioeconomic status who do not receive a regular pension. In 2016 the pension amounted to 93.543 pesos or 135 euros a month. Beneficiaries receive free medical care in the primary health care system and in public hospitals.
- The *Aporte Previsional Solidario de Vejez* (Solidarity Pension Contribution) is a monthly monetary contribution funded by the government to increase self-financed pensions for those whose individual contribution offers them a pension lower than that offered by the basic solidarity pension. The contribution increases their pension to that of the basic solidarity pension. For elders just above the basic solidarity pension threshold, the contribution offers a fixed monthly subsidy. The benefit amounts to, on average, 135 euros per month.

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[56] Market regulation policies, although connected to elderly care, as is the case of conciliation policies, are not included in this study because conciliation policies for elderly care are inexistent in Chile. By contrast, conciliation policies do exist in Chile in the context of child care, for example.

- The *Bono Invierno* (Winter Grant) is a monetary grant of 46 euros given to those beneficiaries of the elderly basic and the elderly contribution pensions. It is given once a year during the winter months to cover any extra expenses.
- The *Bono por Hijo Nacido Vivo* (Grant for a Child Born Alive) is a grant offered to women for every child they birthed or adopted. For women receiving the Basic Solidarity Pension, the grant is added to each pension received. All other women receive a grant the month after they become 65 years old.
- The pension system has now eliminated the 7% health care contribution discount for elderlies.

Through the Basic Solidarity Pension and the Grant for a Child Born Alive, the reformed pension scheme includes women who have been out of the labour market – many times due to caring work responsibilities – into the financial protection system. It constitutes first-ever acknowledgement of women's care work (Provoste 2012) and decreases gender inequalities in access to financial security (Arriagada 2009). However, gender inequalities in pension and women's financial security persist. Adult women pay higher health plan premiums and experience labour discrimination. In old age, they receive extremely low pensions: 94% of retired women receive a pension that amounts to less than 220 euros per month (156,000 Chilean pesos) (Fundación Sol 2016).

Notwithstanding the important advances to offer financial security to the elderly, and the specific recognition that women who have been out of the labour market for long periods have the right to receive a financial protection, pensions in general – and the Basic Solidarity Pension in particular – do not cover major basic needs, let alone care needs. The *Pensión Básica Solidaria*, for example, is set at almost 40% of the minimum wage; 90% of the Chilean population receive monthly pension that amounts to 200 euros or less (140,000 Chilean pesos).[57] Some 45% of the total elderly population cannot cover their basic needs with their pensions, which has resulted in many elderlies returning to the labour force, engage in debt or simply live on the charity of their families (Fundación Sol 2016). A strong public financial support for pensioners is considered in this way a form of de-familisation, as it is aimed at granting the elderly financial autonomy (Saraceno and Keck 2010). Despite efforts, Chile is still far from offering financial autonomy to its elderly.

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[57] As a result of the adjustment to mortality tables published by the pension funds public overseeing body (the *Superintendencia de Pensiones*), as of July 2016, retired people have seen a two percent reduction in their pensions, on average. Mortality tables were adjusted to reflect an increase in live expectancy after retirement age of 10.5 months (Fundación Sol 2016).

4.3.3 Health care

Until the 1980s, Chile's health system was predominantly publicly funded, and health care publicly delivered. Patients from higher-income households could use vouchers to cover some costs of care provided in private centres. The system was highly effective by Latin American standards; Chile's health indicators positioned it among the best health care systems in the region. It significantly reduced communicable disease rates, and improved nutrition and maternal and child health. Infant mortality rate, which had been 136 per 1,000 live births in 1950, dropped to 33 per 1,000 live births by 1980, and the prevalence of malnutrition among children under six years of age dropped from 37% to 12%.

In the 1980s, as part of its market-oriented policies, the military government began allowing salaried workers to opt out of the public health insurance and care system and use the legally mandated 7% wage contribution to purchase private health insurance (also referred to as ISAPRES for *Instituciones de Salud Previsional*). A two-tiered system emerged. Privately-insured individuals accessed private health care; publicly-insured individuals accessed publicly delivered health care. Private insurance companies contracted with private providers, driving rapid growth in private clinics and hospitals. At its peak in 1996, private insurance covered 25% of the population (MIDESO, 2014). The public health system is funded through a public agency, *Fondo Nacional de Salud* (National Health Fund, FONASA). The military government also decentralised primary care centres, shifting their control to municipalities, a feature which remains until today.

During the 1990s, with the return to democracy, the government increased public funding for health care, especially through hospitals. Democracy also brought growing pressure to improve the public system's responsiveness and implement major reform.

In the early 2000s, the government of President Lagos promoted a reform that strengthened public health care provision without abandoning the private health system. The *Garantías Explícitas en Salud* (Explicit Health Guarantees, GES) aimed to improve public-service health quality by guaranteeing services to patients experiencing one or more of 56 selected health pathologies. The programme ensures medical coverage to treat the health problems that cause most deaths, regulates waiting times by law, regulates the amount of co-payments to protect families financially and regulates quality standards in service provision. Access to these benefits is universal. Unlike most public programmes in Chile, access is independent of the income level or age of the beneficiary.

In addition to universal coverage over these selected pathologies, Chile has achieved near universal health coverage with a basic benefit package that all health insurers must provide. However, health financing remains inefficient and inequitable (OECD 2016). The public system overwhelmingly covers the poorest while competing private insurers select low risk populations and apply premiums according to individual risks, penalising women, the elderly and others with greater needs. Chile has one of the highest per capita private health insurance expenditures in the OECD, surpassed only by the United States. Pharmaceuticals are generally not covered in public or private insurance schemes; they are mostly paid through private out-of-pocket expenditure with little public aid, limiting access to proper treatment. The high burden of out-of-pocket spending creates barriers to access health care services (outside of the basic benefit package), particularly for low-income groups and highlights the need to progressively expand affordable health service coverage (OECD 2016).

In the past decade, advances in medical technology and a more efficient hospital management have led to a reduction in the length of hospitalisation and a faster referral to the patients' home. Though more efficient in terms of public use of resources, this has generated difficulties for some families that have to readjust their life to provide care to the frail elderly (Arriagada 2011). As defined by the health system, elderly care continues to rely heavily on the role of families, and more specifically, of women (Provoste and Berlagovscky, 2002).

Health programmes focalised specifically on the elderly population are:

- The *Programa Nacional del Adulto Mayor* (National Health Programme for the Elderly) includes an annual health check and periodic checks of rheumatic, cardiovascular, respiratory and tuberculosis diseases, influenza vaccination, among other checks and medicines. The programme explicitly states the family's role as crucial in care for the elderly: "it is fundamental to understand that any action of the State will not replace an attentive and worried family about their elderly. This is the basis for our elderlies to achieve a good quality of life. Of course in this task the family must be supported by the State with timely delivery of health care" (MINSAL 2015). This programme includes the *Examen Annual de Medicina Preventiva del Adulto Mayor* (Yearly Preventive Health Exam) and the *Medida 6B* (Measure 6B) described below.
- The *Examen Annual de Medicina Preventiva del Adulto Mayor* (Yearly Preventive Eealth Exam) is included in the services provided by the GES programme and is therefore universal. The exam evaluates the elders' health state and functionality and identifies and controls risk factors that may contribute to the elder's loss of functionality. Health professionals elaborate a personalised health care plan after the exam.
- The *Medida 6B* (Measure 6B) and the *Cuidados Domicialiarios para personas con dependencia severa* (Home care for severe dependent persons) began to be implemented at the country level in 2006 through municipality-administered primary health centres. A group of health professional visit severely dependent elderly once a month to provide health care. In addition, through the *Medida* 6B the main caregiver of the severely

dependent elderly receives a stipend of approximately 25 euros a month. The *Medida 6B* also offers caregivers training workshops and/or direct advice at home in basic management techniques and psychosocial support. Family caregivers can access this programme if certified by the programme management at the primary health centres after taking part in the workshops or training sessions.

Coverage of this measure is very limited; access to this benefit is restricted to caregivers of severely dependent elders who belong to the lowest socioeconomic status.

The Health Ministry manages the programme, but informants from SENAMA suspect the implementation does not fully meet the design specifications. "Supposedly, the programme from the Health Ministry for severe dependent elderlies has to certified the family caregivers through their participation in a care-training workshop in order to give them the monthly stipend. But I have strong doubts that they are actually doing it. This is the kind of programmes that reads very beautifully in paper but at the end in the reality it is not done" (Key informant from SENAMA).

Indeed, according to a key informant from the primary health sector working in this programme, this certification is not taken very seriously. Only few municipalities implement the programme seriously. For most, the *Medida 6B* is nothing more than a monetary transfer to the main caregiver. The reason for this is that small municipalities do not have the resources or sufficient eligible caregivers to carry out a workshop for them. Another problem is that the programme does not consider scheduling constraints: if workshops and training sessions are held during the week, family caregivers will have very few possibilities to find someone that can stay with the elderly while they go to the workshop. Only workshops that have been offered on Saturdays have been successful in the municipality where the key informant works.

Notwithstanding the limited coverage and eligibility, and the limitations in certifying caregivers, the *Medida 6B* is an important step in including the family caregiver as a direct beneficiary of a programme. It is a recognition of their care work. Nonetheless, as well as in SENAMA-sponsored programmes, the objective population of this programme is the elderly; explicit attention to caregivers is only to improve the quality of their care.

4.3.4 Chile Cuida

Chile Cuida (Chile Cares) is a programme created by the *Fundación para las Familias* (Foundation for Families) in 2015, under the eaves of the Sociocultural Direction of the

Presidency.[58] Elderly care became a priority for the Foundation under the leadership of its current director, Paula Fortes, a former director of SENAMA.

Chile Cuida offers home care services to elderlies with moderate and severe dependency, allowing them to remain in their homes and in good life conditions. The programme also provides respite for family caregivers, offers family caregivers the option of participating in weekly self-help groups led by mental health professionals and offers caregivers the possibility of participating in care-training workshops and in recreational activities. The programme trains and employs women from the same community who are unemployed or looking to increase their income as formal caregivers. These women visit each participating elderly twice a week.

The programmes' formal caregivers work full time from Monday to Friday and receive as a monthly salary of approximately 500 euros. The programme is funded jointly by the Ministry of Social Development (45%) and the Ministry of Labour and Social Security (55%) for a total budget of around one and a half million euros. *Chile Cuida* began its pilot phase with 100 families in the municipality of Peñalolén. The programme expanded to three other municipalities in the Metropolitan Region in 2016 (Recoleta, Santiago and El Bosque). In each municipality, home care will be provided to 125 elderly people with moderate or severe dependence; a respite programme provided to 125 family caregivers; and 27 people will be trained and hired as formal caregivers. At this stage and for the short term, no mention has been made to expanding the implementation of this programme to any of the country's remaining 342 municipalities.

Importantly, the underlying motivation for the creation of the programme is the ethical consideration that there are situations that human beings cannot solve by themselves or cannot do it without the support from others. In these situations, as is the case of elderly care, the State must play a role. *Chile Cuida* is thus an ethical response to a situation that many Chileans face and many others will face in the future, either as caregivers or elderlies themselves (Dirección Sociocultural 2016). Though praised by its design and the recognition of the role played by caregivers, experts see few possibilities to expand this programme to a national level because its high cost (Key informant, advisor at the President's Office representing MIDESO).

4.3.5 National sub system of care and support

Care systems are beginning to develop in Latin American countries and Chile is not an exception. Care systems can be defined as the set of intersectorial public and private actions

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[58] The Foundation for Families was created in 1990 by Leonor Oyarzún, the first-lady during President Aylwin's government. Since its creation, the work of the Foundation is focalised on low-income households with the objective of strengthening their link to their communities. First ladies usually head the Foundation for Families. During Bachelet's second government, Paula Fortes, former SENAMA director, has led the Foundation.

developed in an articulated manner to provide direct care to people and support families in caring for household members. This includes the care of dependents, including minors, persons with disabilities, the elderly and the sick. It is a central component of the social protection system and is based on the definition of care as a public good, as a right and a dimension of citizenship (Batthyány 2015).

In her 2015 annual address, president Bachelet announced the creation of the *Subsistema Nacional de Apoyos y Cuidados* (National Subsystem of Care and Support, SNAC). This announcement marks the most important recognition of elderly social care needs, recognising not only the elderlies but also their caregivers. The announcement of this sub-system comes along with the "recognition that care is a social right to be deepened" (Dirección Sociocultural 2016). The subsystem is still being designed. It is planned to be part of the Social Protection System already in place. The system's mission is "to accompany, encourage and support dependent and disabled people and their support network. It includes public and private actions, coordinated across sectors, to consider the different levels of dependency." (MIDESO 2015). The idea is to promote the wellbeing of individuals and households with at least one member with a dependency level and or a person with a disability; ensure the coordination and articulation of public and private services; promote the autonomy of individuals and the progression of dependency; lessen the burden of care work of the support network with emphasis on the main caregivers; and establish and supervise the compliance of quality standards for public and private care services. The subsystem will integrate actions in the home, in the community and public institutions, taking into account the preferences and specific needs of dependent persons and their carers (MIDESO 2015).

According to key informants, this announcement is the result of the pressure from different social organisations (NGOs, National Women's Service, community organisations, etc.) who lobbied for the visibility and recognition of the needs of women who are caregivers and the need to improve the care conditions of people with dependency levels (both elderlies and disabled people). Paula Fortes, former SENAMA director and current head of the Foundation for Families which depends on the Sociocultural Direction of the Office of the President, played a key role in placing elderly care in the government's agenda.

The sub-system of care includes the notion of support in addition to that of care to better account for groups with certain specific support needs. The system thus expands the focus on individuals with physical or cognitive dependencies and the health care they need (care) to individuals who can have an independent life (support). In adding support, the system includes people with disabilities, makes it explicit that not every case of dependency and disability needs a caregiver and recognises that both health and social care are needed (Key informant from MIDESO).

The need for a consolidated system highlights how current services offered by the State regarding elderly care are inadequate and dispersed (MIDESO 2016). The system will also seek to respond to the gender and economic inequalities related to care as the consequences of care for the dependent elderly or disabled are felt more heavily by women and the most vulnerable households (MIDESO 2016).

The system will target households with dependent and disabled people and their social support network.[59] For the purpose of the policy, elderly dependent people are individuals older than 60 years old and with some dependency level (low, moderate or severe)[60] and people with cognitive or physical disabilities. Dependent children and their caregivers are not part of this system as they are covered under another social protection subsystem, *Chile Crece Contigo* (Chile Grows with You). Eligibility is based on *selective universality*. Potential participants include more than households from lower socioeconomic status traditionally covered by public programmes, but will still depend on certain characteristics of the elderly, their household, their location, or other characteristics. "[Eligibility is based on] selective universality and not total universality because we are still not in Sweden or Norway" (Key informant from MIDESO).

Different ministries and government agencies have been called to participate in the design of the system. The Ministry of Social Development (MIDESO) is in charge of the coordination, supervision, evaluation and implementation of the SNAC. MIDESO coordinates the technical level of the subsystem and coordinates and conducts the research to make informed decisions. Other Ministries and governmental agencies are involved in discussing the main guidelines of the system, the budget and financing and the implementation. They include the Ministry of Health, the Ministry of Labour and Social Security, the Ministry of Women and Gender Equity, the Finance Ministry, the National Service for the Elderly (SENAMA) and the National Service for the Disabled (SENADIS).

At present, involved ministries and government agencies as well as civil society organisations are compiling a registry of all initiatives related to the care of dependent elderly and disabled people across the country to then identify those that will be part of the SNAC. Working groups gather information regarding the types of services provided, coverage and costs of services, financing strategies, management models and linkages with the local network of services and identification of best practices. "The idea is to lay the groundwork for a system of care, not only from theory but from practice" (Dirección Sociocultural 2016).

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[59] The social support network is defined as the persons with or without blood ties with the responsibility to provide care in a non-paid basis with regularity (at least half working day every week day).

[60] Dependency is defined as the condition that makes one need help from others in daily and/or instrumental life activities.

As part of the effort to identify and develop initiatives that work well, the *Fondo de Iniciativas de Apoyos y Cuidados* (Fund for Initiatives of Support and Care) was created in 2015 to support the implementation of local initiatives presented by municipalities or other public or non-for profit institutions working with elderly people with a dependency condition. In the context of the development of the SNAC, the fund funds projects that work well and can be scaled up to the national level and then be considered as part of the system. The funded initiatives should consider a comprehensive care situation, in order to mitigate the effects of the progression of dependence and the consequences arising from carers' heavy workload. Up to date, there are 31 municipalities that have submitted projects in the areas of home care, day care centres, residential services, initiatives offering respite to caregivers and care training programmes. The budget of the Fund is 327 million Chilean pesos (around 470 000 euros).

The World Bank is engaged in offering technical assistance for the development of the SNAC. The World Bank is reviewing international experience, estimating the potential demand of the SNAC and will offer recommendations for the design of a management model for the subsystem. EuroSocial, is also engaged in technical assistance focusing on the institutional design of an agency to accredit and monitor the quality of service in the system, the financing possibilities for the system (e.g. co-payment services, insurance or other schemes) and of developing teaching material to improve community-based programmes. The Gender Division of the Economic Commission for Latin America and the Caribbean (ECLAC) is also engaged to strengthen and ensure the gender equity across all programmes that will integrate the SNAC.

The SNAC is expected to begin a gradual implementation in 2016. The budget for 2016 is 420 million Chilean pesos (around 600 000 euros). No further details are available with respect to the programme and its implementation.

4.4 The main barriers and challenges faced by Chilean policies and programmes for elderly care

In spite of the important steps and efforts, Chile still lacks adequate care coverage for the elderly population (Batthyány 2015).

Chile has made very important advances in offering social protection in general terms. Since the 1980s, Chile moved from a model of maximum private responsibility for the care of dependent people, to a state productivist model with supported familialism, at least with respect to childcare policies. In general terms, the State has increased its role but acts functionally to compensate for market limitations and failures. The family, and particularly women, still assume most of the care responsibilities. For elderly care, the family and women's role is even stronger and receive less public recognition.[61] The State's role in the care regime focuses primarily on supporting low-income households. For the large share of families above the threshold for eligibility, it is the family, *by default*, that assumes elderly care.

In terms of offering social protection, the advances the Chilean government has made are most evident in the expansion of its role and coverage in offering education, health and financial security. They are also seen in the elderly population's access to pensions and health care. They do protect the elderly, and lighten individuals' and families' concern about the health and financial security of the elder. However, coverage remains low – the Basic Solidarity Pension fails to cover all basic needs and only a handful of pathologies are covered under the GES Health plan. The creation of the National Service for the Elderly (SENAMA) and the announcement of the implementation of a National Sub System of Care and Support mark significant progress in the recognition of the elderly and their care needs and establishes an institutional infrastructure from which to develop coverage and organise programmes.

Despite the advances in the public provision of protection and services for elderly care, families provide the larger part of welfare. For most dependent elderly, the family is the sole provider of care and this provision is usually concentrated in one main female caregiver. Though a few initiatives exist to support elderly care and/or the caregiver, their benefit level is low and their coverage is restricted to a very small proportion of the population (Arriagada 2011). The forthcoming National Sub-System of Care and Support may strengthen the weak presence of the State, but it is still too early to analyse its impact. The SNAC is currently being designed and details are not available.

The lack of support means that care for the dependent elderly, as highlighted numerous times, takes place inside the family. It is often inadequate and/or comes with an overwhelming pressure to the family (SENAMA 2009b) and with a high emotional and economic cost for them (Marin 2006). There is little in the way of policies to alleviate the care work of families and to supervise or promote good quality elderly care. This study's Part Three explores, in full detail, the experience of family caregivers in a system with little public support for care.

As gathered from interviews with experts on the evolution of the welfare and care system in Chile and key informants from within government ministries and agencies, several obstacles have prevented the development of care policies for the elderly and their caregivers. They are political and cultural (e.g. the slow recognition of elderly care as a shared social responsibility), institutional (e.g. SENAMA's original ambiguous status, the difficult coordination and communication between health and social services, the nature of a decentralised and unequal

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[61] It is not a Chilean exception that care for the elderly is less recognized than childcare. Among most European countries, with the exception of Portugal, policy measures related to childcare are more developed as well (Saraceno and Keck 2008).

system with low supervision) and economic (e.g. elderly pensions remain low). Along with identifying obstacles for the development of social policies for the elderly care, experts interviewed for this study identified some remaining challenges for the Chilean government. They include, for example, the creation of conciliation policies that would allow to combine the elderly care work with a paid activity. Conciliation policies in the context of elderly care are, as of today, non-existent in Chile.

4.4.1 SENAMA's original ambiguous status

According to some key informants, there are elements regarding SENAMA's original institutional design that shed light on the limitations of the current institutional setup in handling the Chile's elderly care needs. For example, some argue that its size is too small and relevance too low given the needs. SENAMA was developed in a period of modernisation of the Chilean State, which, at the time was equivalent to reducing the size of the State. In discussing its creation, some politicians alluded to the incoherence of creating one more organism within the State, while other politicians argued that SENAMA's size was too small to accomplish its objectives (Huenchuán 2016). The ministerial dependence of the institution is another institutional limitation. At the beginning, SENAMA was created under the eaves of the *Ministerio Secretaría General de la Presidencia* (Ministry of the General Secretariat of the Presidency which liaises with Congress to promote the government's legislative agenda, SEGPRES) as the National Committee for the Elderly was linked to this ministry. SENAMA remained at that level for ten years, even though SENAMA and SEGPRES have a very different nature and relate to different areas of work within the public administration. This lack of logical connection affected the management and SENAMA's institutional recognition. In 2011, SEMANA changed its dependency to the Ministry of Social Development. The ambiguous nature of the functions assigned to SENAMA (coordinate, create or run programmes), its small size and its excessive centralization were not extensively discussed and changed during the transition to another ministry. Despite these institutional limitations, SENAMA has been able to grow and consolidate, having today an important position and visibility (Huenchuán 2016). Its budget is 65% higher than in its origin, in 2003 (Kornfeld et al 2016).[62]

4.4.2 The slow recognition of elderly care as a shared social responsibility

Despite its relative urgency and compared to other welfare policies (e.g. maternity leave, childcare support, education), policies that redistribute the elderly care so it does not fall uniquely on families, and women therein, have progressed slowly (Provoste 2012). Most

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[62] Specifically, SENAMA is an autonomous service with its own budget, which is administered and discussed independently of the Ministry of Social Development. Every year, its directors defend the budget to Congress, highlight their achievements and point to potential improvements (Kornfeld et al 2016).

advances in elderly care are only recent; so is the increase in public interest. The role the State can play in the provision of care for the elderly is in competition for resources with the needs of other population groups; politicians and policy makers generally think the limited resources should be allocated for children (Guzmán and Huenchuán 2005). The weak political visibility of the elderly is explained primarily by the gender-biased division of labour inside and outside the home; but also by the persistence of cultural models that consider that care should be private and provided by women inside the families; by labour markets institutions and legislation that do not support workers' family obligations; and by the absence of a legal framework that promotes the social responsibility of care (Arriagada 2011).

Both an expert from SENAMA and a geriatric doctor working in a primary health centre agree that the elderly have no social value from the perspective of the Chilean society and the government.

> *The issue of family care is not a priority for the government because there is a cultural thing behind. Culturally, the elderly is not valued. (Key informant from a Primary Health Centre in a municipality from the Metropolitan Area)*
>
> *[Chile] must change the social regard to the elderly; we cannot display images of the elderly in school books where they appear knitting on a rocking chair. The elderly must be positioned as a subject with rights. All this [takes place] in the context of an extremely individualistic society, of a tremendously mercantilist society, one where the elderly who stops working is useless, is a burden. If you talk to any elderly person that is active and autonomous, the person will tell you that, besides his age, which they will never tell you, they don't see themselves as an elderly. Because elderlies in Chile are those inactive and unproductive, those without any value. Why would the Chilean government put its priority in such a group? (Key informant from SENAMA)*

Aging in Chile brings about a "social death". Elderly people are no longer valued and often infantilised. Identity in Chile remains heavily linked to work; when someone stops being productive or able to produce he or she loses their social role and social value. Retirement should be an opportunity for elderlies to build their identity in non-economy related areas, accompanied by a society aware of the value of the elderly, but this is not the case in Chile (Fundación Sol 2016).

The hypothesis of delayed policy attention due to low cultural value and subsequent low political attention received by the elderly is supported by the fact that policies towards children in Chile have had an earlier development and receive a higher budget allocation. For example, SENAMA, as a whole, has an annual budget that is almost 50% lower than that of the child development support system *Chile Crece Contigo* (Dirección de Presupuesto 2016). This entails that *Chile Crece Contigo* can have universal coverage and include all children under 4 years of age and their mothers who are in the public health system. SENAMA's programmes, by contrast, are restricted in terms coverage, limiting eligibility to elderly and covering in practice a minor part of the elderly population who can benefit from these programmes. Public policies could drive this relationship and enhance the cultural and political value of the elderly. Public policy has failed to give elderly care the space and recognition it needs for care to acquire social value. Public policy has been unsuccessful to create space for the elderly in the public realm, failing to allow the elderly to interact with broader society and other generations. This failure keeps the issue of elderly care as a low-priority issue.

> *The scarcity of value and the low visibility of the elderly care issue is because there are very few public policies that take into consideration this population and give them the deserved space they need in the public agenda and in public spaces, so that the society can literally see and share spaces with people from older generations. (Key informant from SENAMA)*

Though still not disclosed publicly, an expert working in the design of the *Subsistema Nacional de Apoyos y Cuidados* (SNAC) mentions that one of its goals is to give more visibility to elderly care so that it is assumed as a shared social responsibility instead of a private family issue. The SNAC plans to increase the State's and the community's role in elderly care. Communities have been left out of welfare provision and general civic participation from the 1970s, when military government disarticulated community organisations.

> *It is necessary to make this issue visible, raise it so that citizens and the State do not continue to be absent; and that communities, neighbourhoods, take part of this. The community has a very important role to play. (Key informant from MIDESO)*

Huenchuán (2016) illustrates the lack or low level of social recognition that the elderly have in Chile, in a comparative study on aging and public institutions in Latin America. Results show how the development and creation of SENAMA follows a different trajectory than that of similar national services for the elderly in other countries in the region (e.g. Argentina and Mexico). SENAMA was not the result of an increased societal awareness of the importance of the elderly or a recognition elderly's contribution to society. Quite the opposite, SENAMA was tasked with the goal of raising awareness and sensitisation of the value of the elderly given the low recognition levels for the elderly in Chile.

4.4.3 The lack of coordination and communication between elderly-related services

There is a marked division in Chile in terms of the institutions and actors in charge of elderly issues. It affects the coordination and communication among these services. The National Service for the Elderly (SENAMA) that depends on the Ministry of Social Development (MIDESO) is in charge of the elderly care programmes but is not involved in the development, design or implementation of programmes related to other transcendental aspects of the elderly welfare and care, as the pension or health system. The pension and health systems are part of a different network of actors and policy makers. This lack of institutional linkages fragments policies related to elderly care. Acknowledging this fragmentation, one of the MIDESO's major goals is the coordination, implementation and evaluation of social policies, plans and programmes, but this role is usually played within the institutions and social programmes under its wing, leaving out, for example, health, housing, pension or other policies. In the case of elderly care, MIDESO coordinates SENAMA's policies and programmes with other programmes within MIDESO, but does not reach out to institutions responsible for the elderly health or pension issues. Despite the effort to institutionalise the coordination, elderly care policy and programmes remain fragmented, leading to, among others, duplication and an inefficient use of resources.

One evident form of duplication and lack of coordination is evidenced in programmes to support elderly care at home and offer respite to caregivers. The few resources available for these programmes are not used efficiently. The Ministry of Health coordinates the Elderly Care Programme that provides home health care and a monetary stipend to the main caregiver of an elderly with severe level of dependency (the *Medida 6B*). Municipalities implement this programme through their primary health centres. In parallel, SENAMA offers the *Cuidados Domiciliarios* (Home Care) programme – also implemented by municipalities, though through their social services – which offers social and health care services to dependent elderly people living at home and offering respite to their family caregivers, by visiting them once a week for two hours.

Both programmes rely on the same instrument to measure the elderly's dependency and determine their eligibility into the programme. The instrument, however, is applied separately because there is no transfer of information between the professionals of each programmes, even though they both work within the same municipality. An elderly undergo the same diagnostic tool twice. There is neither an instance nor a channel for the respective professionals to discuss the elderlies' progress or develop a complementary action plan for each elderly's social and health care. The National Programme for the Elderly facilitates reaching out to potential participants because the public health insurance includes a yearly preventive exam with a measurement of dependency to all elderlies. Professionals working for SENAMA's programme do not have access to this information and must find other ways to reach out to potential beneficiaries.

Collaboration between health and social services is hindered by the 2014 law limiting patients' health information transferability. Lack of efficient coordination is not solely the cause of this law; lack of coordination is also seen between health professionals within the same primary health centre. It is common for yearly preventive exams for the elderly to be carried out multiple times in one year, even though results are already there. Primary health centres receive money from the Health Ministry if they conduct the yearly preventive exam that also measures the dependency level. Usually a nurse conducts the exam, but a doctor in the same primary health centre will also run the same exam because of a lack communication with other professionals and no incentives to maintain records or review them (Key informant, geriatrician).

The integration of care and support initiatives under the Sub System of Care and Support attempts to promote coordination and the integration of services for elderly care. Coordination and articulation of public and private services is the system's second main objective, recognising the need for an integrated policy framework to address elderly care and not just fragmented initiatives, as has been the case so far.

Integration and coordination is particularly difficult in elderly care, where the family plays an important role. Health professionals acknowledge the need for "health and social services to have a more institutionalized and coordinated response to this population [the elderly] and that can serve as support also for their families" (Key informant, health professional in a primary health centre).

Yet the design of the sub system itself lacks clear communication. Although good communication exists between the agencies involved in designing the SNAC, until the drafting of this chapter, MIDESO was still waiting for the health sector to provide the actual number of dependent people in Chile, a key figure for the design of the system.

> *The data exists, the problem is to get it. People from the Health Ministry have told us they will provide us with that data but we are still waiting. It is mainly because of this law protecting patients' information and their ethics committee, but we are not asking for their names or their medical records, we are just asking for the number or dependent people and their socioeconomic characteristics, we don't want to identify this people by their names. I really don't understand why it's taking them that long. If they are not committed it is not worthy to build this System without the Health sector. Everything should be digitalized and in a network system. (Key informant from MIDESO)*

4.4.4 Decentralization and the unequal distribution of resources across municipalities

Decentralization in Chile takes place in a politically centralised structure. Social policies originate in the national administrative and political centre. They then move to municipalities in different regions of the country for implementation. This social policy implementation design makes the actual implementation of policies and programmes dependant on the local interests of those who govern a municipality. In the context of elderly care, several municipalities with a high percentage of elderly population in need of care do not implement any of the SENAMA's programmes; other municipalities implement them all. The adoption of elderly care programmes remains at the discretion of local governments and the mayor's political priorities. If their priorities differ from elderly care, they won't implement SENAMA's programmes; if their priorities shift (e.g. as a result of electoral changes) the implementation of programmes can be discontinued on short notice.

Even if implemented, policies and programmes can fail to bring expected benefits. Though in principle municipalities run public policies, design, resource allocation and technical direction are centralised. Local governments have, in fact, very little autonomy in this context of *operational decentralization* (Raczynski and Serrano 2005). Elderly care related programmes, designed at the central level, often do not take into consideration the local contexts, specific needs and population characteristics. They usually cover a problem partially or lack the legitimacy at the local level. Signals sent from the central level to public and private bodies at the local level are sometimes unclear, hindering proper implementation. Centrally-designed policies are often unrelated to regional development plans, as each originates from different central bodies (Podestá 2001).

Given the high diversity among the Chilean regions and among municipalities, decentralisation could be an asset by giving local governments' autonomy to adapt programmes to their own needs and population. Yet municipalities differ in their economic and resource capacity. For resource-constrained municipalities, autonomy and space for political priorities to determine the implementation of programmes accentuate inequalities between municipalities and among its inhabitants. For elderlies and their caregivers, this situation increases their disadvantage when compared to those living in other municipalities with more resources and political engagement with elderly care and their primary caregivers. Chapter 6 provides examples on how living in a particular municipality affects access to programmes and services, and how the uneven distribution of programmes and services becomes a constraint for main carers.

Often, municipalities, especially the poorer ones, do not have the capacity to implement the programmes adequately, failing to reap the benefits of the programme even though resources were spent. For example, people working at the municipal level interviewed for this study mentioned that they implement SENAMA's programmes in their municipalities, but do not have the resources to implement them adequately. They need more technical support from SENAMA given that they lack the autonomy and capacity to adjust the programme to their local context and needs.

> *We need from SENAMA clearer orientations in some subjects such as emotional support for the elderly, in kinesiology, etc. There is no a clear line of where the programme should go. There are no technical bases to know where we should go. (Key informant, person working in a Day Care Centre in a municipality of the Metropolitan area)*

SENAMA asks municipalities to conduct an assessment before the implementation of the Home Care programme and an evaluation at its end, but there is no evaluation or instance for feedback in the middle of the programme implementation.

> *We need to know if we are doing well or not, they [SENAMA] just tell us 'do it'. They are asking us to do what we can with the limited resources we have. It is from our own*

> *initiative that we created manuals for the intervention so that the formal caregivers we hired have clear guidelines of what they should do and they can transmit their knowledge to the family care. (Key informant, person working in the Home Care programme in a municipality of the Metropolitan area)*

Given the autonomy that municipalities have in terms of the decision to implement or not a programme (granted by the operational decentralization of the system) and the small budget received from the central government, in elderly care programmes and others, the quality of implementation depends on the good will of professionals working at the local level. There is a lack of central supervision or quality standards and the autonomy in implementation coupled with the low resource allocation from the central government hinder municipalities' capacity to adequately implement programmes.

> *The per capita allocation for each elderly in the programme is very, very low, and many localities do not have the infrastructure and human resources to take good care for elderly people with some level of dependency. If implemented, the programme usually does not work well and if it works well it is because of the human resources and their own motivations, by ethics rather than by an issue of resources, because these are not enough to implement them. (Key informant, a professional implementing a care-related programme designed and financed by SENAMA)*

4.4.5 The low coverage of services and support for the middle-income class

The focalisation principle of public policies in Chile aims at protecting the lower socioeconomic groups through focalised policies that benefit the most vulnerable population. A welfare regime like the Chilean carries out important efforts to ensure that the poor improve their living conditions. These policies have helped the poor and lifted many households out of poverty. The non-poor, however, rely largely on private solutions for their needs. Individuals from middle-income sectors are not covered by focalised policies and are excluded from ineffective markets (Martínez 2008). While the State supports lower-income groups and economically advantaged groups are able to buy services in the market, medium income households are more likely to develop strategies relying on family networks to protect their members (Del Valle 2011). The large section of the population with medium-level income may have sufficient income to avoid being labelled vulnerable; it is high enough to be excluded from public support but still low to access to the market for services like care services (Martinez 2007). Positioned between public support and market access, they are deprived of adequate social protection and, in particular, support for elderly care. Broad sectors with low - but not extremely low - wages are not adequately covered in their fundamental rights (Acosta 2013).

The middle class resolves its care needs privately, using the more practical and least expensive alternative from the perspective of the needs of the family and the care recipient, often relying on informal care arrangements by family members, often daughters or daughters-in-law (Acosta, 2013). The growth in female labour force participation seen in the past decades in Chile and Latin America have contributed to enlarging the size of the middle class in the region, but the change in women’s role in the labour market has brought neither a redistribution of care nor a strengthening of the social delivery of care to support this evolution in gender roles (Arriagada and Sojo 2012).

In reviewing the Chilean context of care and social policies, CEPAL (2000) considers essential to ensure the universality of care policies and benefits aimed at people who need assistance and those providing care. They stress, however, that universality does not remove the need to exercise some targeting to ensure the financial viability of programmes.

4.4.6 Elderly pensions are, at best, low

Despite the significant progress made in terms of increasing financial security for the elderly through increased access and levels of pensions, pensions in Chile remain, on average, too low to meet basic needs; being elderly is generally synonymous with being poor (OECD 2015b). Given that public support services for elderly care is weak, when an elderly requires permanent care, the financial implications fall almost exclusively on families. Families carry on the risk of an elderly becoming dependent. Often, families do not have the physical or financial capacity to assume this risk bringing about financial insecurity in the household and exit from the labour market, among many other consequences discussed in Chapter 3. The relationship between financial security of the elderly and its spillovers on future generations when they require care has not been reflected at all in the policy discussion (Provoste 2012).

The pension system is segregated between those that participate in the private pension insurance scheme and those that participate in the public scheme. The private pension fund is a private insurance scheme, pensions are proportional to the individual savings and, depending on the retribution scheme chosen, may run out during a person’s retirement. Public pensions are generally lower and only minimal to cover basic needs. The average retirement pension in the private system is 182,000 pesos (approximately 260 euros). This amount that can barely cover an elderly’s care and daily living costs, let alone the costs associated to some form of dependency. Less than 20% of the elderly in the private system report that they can meet their needs comfortably with their pension (Fundación Sol 2013). Beginning in 2008, all elderly are eligible to a *Pensión Básica Solidaria* (Basic Solidarity Pension) amounting to 95,543 pesos (135 euros) a month. The elderly’s low income impoverishes the carers’ household and makes it difficult to externalise part of the caring tasks.

Not only are pensions relatively low, but health and medical care costs are high, with Chile having one of the highest out-of-pocket health expenditures in OECD countries (OECD 2015a).[63] Pensions do not allow users to pay for health care not covered by the public health system. In the event of the elder requiring emergency care, family carers sometimes avoid the emergency unit of the public system and decide to pay for private health care to ensure care quality, which comes with a high cost, and in most cases significant financial debt.

For an official in the Ministry of Health, an increase in pensions won't solve the elderly care situation but is part of an equitable solution.

> *There is a structural problem with pensions in the country and the issue needs a major revision and reform. The pension system has made some people very rich [the administrators of the pension fund], but not those who retire. If you are a woman who retires at 60 with a life expectancy of 85 years your money will be gone way before you die so then [the financial burden falls on] your children, or [if you opt for a life-insurance retribution scheme] the same pension is not [high] enough for anything. Your financial revenue [is already low], and as people get older their needs grow, especially from the medical point of view. In Chile we do have money,[64] but that money is in savings, I do not understand why we keep it, if you are having important needs and begin to accumulate elderly people then eventually the State will have to care for them, like it or not. Imagine a person who worked all her life, raised a family, maintained her children, purchased a house, even then her pension is not enough for anything. If that person gets sick, she will not have Isapre [private health insurance] but will be enrolled in Fonasa [public health insurance] and will have to go to a public hospital, and it is the State that takes care of the public hospitals. Then, in the end, the State will have to pay. (Key informant, a researcher from the Health Ministry)*

Discussions on reforms to the pension system have developed during president Bachelet's second government. She convened an expert commission (known as *Comisión Bravo*, the Bravo Commission for the economist who led the commission) to recommend changes to the pension system. Given the government's inaction with respect to the commissions' conclusions, the discussion revived after a series of public protests highlighting low pensions and the perceived inefficiency of the private pension system. The financial precariousness of the great majority of the elderly has gained visibility and political importance, but no political consensus exists on how to reform the system.

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[63] Despite the last decade's progress towards establishing a more generous and universal health care system, the Chilean population still draws heavily on out-of-pocket expenditure to get the needed and desired health care.

[64] Chile has a large sovereign wealth funds valued at more than 20 billion USD (the *Fondo de Estabilización Económica y Social*, Economic and Social Stabilisation Fund). In addition, since 2006, the government constituted the *Fondo de Reserva de Pensiones* (Reserve Pension Fund) which has an estimated value at the end of 2015 of 8 billion USD. The Reserve Pension Fund is expected to support the funding of the Basic Solidarity Pension when it is unable to finance it. In 2015, the government did not extract any funds. The government adds, every year, 0.2% of its GDP to the fund (0.5% in years of budget surplus). The fund has grown more than 10-fold since its creation in 2006 (Ministerio de Hacienda 2015).

Experts point out that the problem for care systems is not the projected increase in the elderly population. The main problem lies in the fact that society has not created the institutional, social and financial conditions to tackle the phenomenon and its consequences. In this regard, the attempt to improve the financial revenues through retirement pensions is an important step. However, although pensions are a key element to guarantee for a good quality of life in old age, it is not the only one. A pension reform alone will not solve the many problems related to the aging population and the care load this represents for Chilean families and Chilean women in particular (Acosta 2009).

4.4.7 The lack of conciliation policies to balance care work with paid employment

The conciliation of work and family life based on the redistribution of care tasks between the State, the market and families remains the blind spot of public policy in Latin America (CEPAL 2010). Chile is not the exception, especially when it comes to elderly care. Policies to promote gender equality have been implemented, but economic, social and political institutions continue to operate under the assumption of a strict gendered division of labour that maintains the stereotype of women as caregivers and men as income providers (Batthyány 2015).

In general, the Chilean population lacks public alternatives to support the balancing between a paid job and care work. This is particularly the case of elderly care, but also of childcare or other forms of care. Policies and programmes that seek the conciliation of work and family-care are weakly developed in Chile. Families from higher income status can access market solutions to buy care alternatives for their dependent family members. Middle- and low-income families do not have the means to access elderly care services in the market nor can access government-provided services. Where present, conciliation policies focus exclusively on dependent children. There are no conciliation programmes for carers of the dependent elderly.

Chile is not an exception in this regard. In developed countries the development of elderly care policies is also far behind that of childcare. In European countries, for example, the work/family conciliation policies have increasingly become part of employment-led social policy (European Commission 2007). The main concern is with respect to childcare and how parents, and mothers in particular, are able to balance childcare and career prospects (Gornick and Meyers 2003). Much less attention has been paid to caring responsibilities at the time parents or relatives become dependent and need care (Saraceno and Keck 2010).

Conciliation policies in the context of childcare take the form of maternal or paternal leave; they benefit caregivers who are in formal employment. The State has begun to develop initiatives to improve the supply of free public childcare services through an increased number of childcare centres and mandatory kindergarten under the *Chile Crece Contigo* (Chile Grows with You) programme.

In the context of elderly care, the government has expanded space in elderly residences, but, as mentioned earlier, the few spaces available are first allocated to elderly without family members who could care for them. The implicit assumption is that the family should care for the elderly. There is still strong unmet demand for care (Arriagada 2011). Experts interviewed for this study point to the fact that it is not uncommon for nursing homes to call the elderly in the waiting list to offer them a place, only to find out they have passed away months before the opening was made available for them.

Provoste (2012) observes a fragmented approach to tackling the care needs of different social groups. Although there are important differences between the care for the elderly and childcare (Sareceno and Keck 2008; Le Bihan, Martin and Knijn 2013), both care tasks rely on family members and women in particular. Several women, due to the inability to balance care and paid work remain out of the labour market. Provoste (2012) notes that there are synergies in conciliation policies for elderly and childcare given that it is women doing the care work in informal, unpaid agreements, but these synergies are not taken advantage of. The recent announcement of the National Subsystem for Care and Support is a missed opportunity in this direction. It includes care of the elderly and individuals with disabilities, but leaves childcare out, reducing the possibility to take advantage of synergies between elderly and childcare.

A key informant from the Ministry of Women and Gender Equity (*Ministerio de la Mujer y la Equidad de Género*) points out that one of their objectives is to promote conciliation by motivating employers to promote a better balancing between their jobs and family life among their employees. The Ministry offers, for example, seminars to disseminate best practices. But there are no laws, no public policies aimed at obtaining a good balance. Also, the Ministry focuses on the promotion of conciliation among employers, but pays no attention to the balancing needed for people who have left the labour force but would like to work.

Certain firms, especially large firms, have become an important proponent of conciliation initiatives in the context of their corporate social responsibility strategies. Certain large firms offer diverse ways to strengthen the family-employment balance and community through maternal and parental leave, but also through recognition (celebrating parties with family members) and offering support in situations of family conflicts (Provoste 2012). These practices are generally aimed at improving productivity as well as increasing employee satisfaction (OIT and PNUD, 2009). However, most of these initiatives focus exclusively on childcare and do not consider elderly care at all.

It is not enough to advocate for the conciliation of paid employment and care for women. Conciliation measures require redistributing the joint responsibility of paid and unpaid work between families, the market and the State, with an increased role by the part of the State and a more equitable distribution inside family members. Strategies to reconcile care and paid work must include formulas involving reconciliation of paid work and unpaid work not only for women but also for society in general. This can take place within homes, but can also be made and encouraged from State regulatory actions, fiscal and social service provision (CEPAL and ONU 2009).

In reviewing conciliation policies in Latin America, the International Labour Organisation and the United Nations Development Programme (2009) argue that reconciliation policies have had limited impact. While, as noted above, there have been development in the laws regarding parental leave, there has not been a redistribution of the care tasks, nor has there been a significant increase in the provision of public services in support of these tasks. Parental leave regulations apply only to those in formal employment, severely limiting its scope in a region with high labour market informality or high prevalence of self-employment (Orozco 2010). Take-up for paternal leave remains very low, either because the workplace is not favourable to men taking up leave or men choose not to take it (OIT and PNUD 2009). Overall, conciliation practices have focused on the delivery of childcare facilities for formal workers, limiting their potential for redistributing care responsibilities beyond the formal sector and without any focus on elderly care support.

4.4.8 Social policies maintain gender inequalities

The beginning of the XXIst century shows significant progress in policies to promote gender equality in Chile. In general, policies implemented have attempted to mitigate gender inequalities in various domains. They have been relatively successful in reducing inequalities in financial security, education and health, for example. Interventions have been less successful in promoting women's employment, in promoting a culture of joint responsibility in the care of dependent people and in developing institutional policies that allow for greater equality in employment and care. Despite the advances, strong gender inequalities remain in the social protection system (Robles 2012).

Also, women have held less power in institutional and political spaces. Women also provide most of the care and bear most of its consequences, but their weaker institutional representation has limited the possibility of considering the gender bias in the distribution of care as an important issue (Aguirre 2007). Policies and government initiatives around care have occupied a secondary status. When they exist, they are seen as a benefit for women, resulting in a symbolic and social devaluation of care work and enduring the assumption that care is a feminine responsibility (Provoste 2012). Using Leitner's (2003) typology, social policies in Chile are *gendered familialistic policies* that assign family care to women, with direct implications for gender and social inequality (Saraceno and Keck 2010).

Public policies and programmes continue to consider care as women's issue and one that the State may (or may not) support. Care is not recognised as a universal human right. There is no discussion around the need to redefine gender care roles (Pautassi 2007).

Indeed, policies in place maintain the gender-biased distribution of care. Public services to support care for the elderly, whether from SENAMA, the Ministry of Health or the Foundation for Families do not have the objective of promoting a gender-equal distribution of care. For example, the *Chile Cuida* programme employs women from the community to become formal carers and give a two-hour per week respite to family carers. The programme boasts its ability to employ women in the community, but never mentions the possibility for men to become formal caregivers for the programme. The programme assumes care is feminine. The same is true for other programmes. For example, the subsidy given for every children is intended for mothers only; it excludes fathers, assuming (and perpetuating) the fact that it is the mother who dedicated years out of work caring for their children. These examples show the long path that remains for Chile to reduce the gender bias in the distribution of care.

Conciliation policies enacted recently also serve as an example of the lack of efforts and incentives to ensure that care provision is shared on equal terms among male and female family members in Chile. Although only related to childcare because they don't exist for elderly care, current conciliation policies benefit only women or have weak incentives to be used by men.

For instance, those who become fathers have the right to a five-day paternity leave to be taken within the first month following birth. However, while maternity leave is State-paid and lasts six weeks prior to the expected date of birth and twelve weeks after giving birth, paternal leave is paid by employers, making it difficult to ensure that the benefit is actually offered and taken up. In fact, only around 20% of fathers use it. The law for maternal leave also offers the possibility to transfer some weeks to the working father, starting on week seven, in which the distribution of weeks is decided by the mother. Only 0.3% of families have opted for transferring the leave to fathers (Comunidad Mujer 2016).

Another example is the mandate that working places with more than 20 female employees must provide childcare for their workers. This measure can increase employers' propensity to discriminate against women in hiring decisions. As such, these policies may actually aggravate the gender gap in the labour force by encouraging employer discrimination against women. Theoretically, mandated employment-based care could allow or encourage use by fathers but no such cases exist in Latin America (Blofield and Martínez 2015).

The existing conciliation initiatives show an increase in the role of the government in care responsibilities or at least some attention to the issue. Despite the effort in supporting families in caring responsibilities, current public efforts are a reflection of *gendered familialistic policies.* They reinforce the idea that caregiving is solely a female responsibility.

Pension reforms such as those implemented in Chile (but also in Uruguay and Argentina, among others) show a different trend. They improve women's financial security through mechanisms such as ensuring a basic pension for all. The gender pay gap, earlier retirement age, interrupted careers and longer life expectancy mean that women's pensions are far lower than men's. The basic pension tops-up low pensions and guarantees a pension for women who never contributed. This programme thus includes the many women who had a history of unpaid work in their home and offers some sort of monetary compensation for the years out of work spent raising their children. This is an unprecedented recognition in the Latin American region for unpaid family care work (Provoste 2012) which marks an important step. Given the lack of options for women when it comes to care, State policies to promote gender inequality should allow people to choose whether they wish to care for their dependents (children, people age and dependency) and offer protection and support (CEPAL and ONU 2010). Currently, however, public policies assume by default that women do want to care, maintaining or increasing gender inequalities.

The lack of policy initiatives to promote gender equality appears in the context of a political priority for poverty reduction. Gender equality's lower priority has limited the application of universal criteria and has expanded the focalisation of social spending. The disregard for gender issues in care for dependent people has served to maintain a *maternalist* model in social programmes, with focalised poverty alleviation programmes assuming that women provide – and will provide - care. The redistribution of care across gender in the broader social protection systems is still far from mainstream public policy. The design and analysis of social policies do not consider care as a shared responsibility. They do not consider that equal participation of women and men in all spheres of life yields better and more lasting economic and human development (Provoste 2012).

4.5 Conclusions

The Chilean welfare regime is primarily a familialistic one. It relies heavily on families to provide care and, within, families on women. After reviewing the development of the Chilean State's role in elderly care, we can conclude that a majority of families still provides care for the great majority of the elderlies because there is no other option for them. In the Latin American context, where all countries are familialistic regimes to some extent, the Chilean welfare state has been labelled as state productivist, one where the state has begun taking a more important role in insuring against social risks. This role, however, only compensates for the market's shortcomings. Social protection still relies heavily on the private domain as a way to ensure social protection against risks, such as being an elderly in need of care. The State plays a relevant role among groups experiencing the highest vulnerability and, with the exception of few policies with universal coverage (such as the public health system of explicit guarantees), is practically absent for the rest of the population.

The Chilean government has expanded its role in elderly care. Notable advances have been made since the return to democracy in the 1990s and a much stronger advance in recent years. The elderly care is already in the political discourse, which denotes an important first step in the development of any public support, that of recognising the phenomenon and its urgency. Especially dedicated institutions (e.g. SENAMA) exist, providing the institutional basis from which to expand current programmes and develop future initiatives. Since the foundation of SENAMA, the announcement of the creation of a National Subsystem of Care and Support is the most recent and salient step taken by the government to recognise elderly care and advance towards a more equitable distribution among society's actors.

Despite these encouraging developments, there is still much room for improvement to create a more equal distribution of care across the family, the State, the market and the community. This chapter identifies a series of obstacles that have hindered the development of a more active government role in supporting the elderly care needs of the country. These include the lack of coordination and communication between elderly-related services, the slow recognition of elderly care as a shared social responsibility and the decentralised structure of the government with an unequal distribution of resources across municipalities. As a result, central and local governments are slow in adopting a more active role in providing options for elderly care so that this role does not fall exclusively on families, reproducing the gender and social inequities associated with a familialistic care regime. Certain elements require urgent consideration to obtain a more equitable distribution of the elderly care responsibilities: low coverage for services and support for the middle-income class, low pension-related incomes, the lack of conciliation policies to balance care work with paid employment and the extent to which current social policies maintain gender inequalities.

For the vast majority, elderly care in Chile remains largely the responsibility of female family members in informal, unpaid arrangements with little support from the Government. Chile thus remains a familialism by default regime. Despite the recent recognition of the issue, it deserves further public attention and action. Given that policies cover a small fraction of the care experience and a large part of the care phenomenon takes place within households, we need then to explore how it is experienced by those that assume the everyday responsibility for the elderly care to understand the elderly care phenomenon in Chile.

Characterising the Chilean elderly care regime as an *unsupported familialism* does not explain what it means to live under such a regime for those provide care. The typology does not say much about what their day-to-day experience is like or how intense it is to provide care to an elderly family member. The next chapter explores the experiences of elderly care by those family members who provide care. It analyses care from a micro perspective to provide a comprehensive overview of elderly care and, ultimately, illuminate the design of public policies.

Part Three: The experience of family carers of an elderly in need of care

> *For me, every day is just like the other, no holidays, no parties, nothing. I get up at 5h to change my mother's diapers. I then sometimes go to bed again until 8h when I change her diapers again and give her first daily medicines. Sometimes I stay awake from 5h. I take a shower, I put the kettle and after changing her I give her breakfast, at 9h. I then do the housework, and then I cook. Whenever I can, only if my mom is sleeping and if I am done with everything else, I lay somewhere and I fall asleep, around 17h, but it's not that I can do it every day. Once in a while I get out of the house in the afternoons, just to buy bread, then I come back running, and if the weather allows I put my mom in her wheelchair and I take her for a walk around the neighbourhood… At night I am so tired I do not even get inside the bed sheets, I put my head in the pillow and I forget about everything. That's my life. My mom comes first; she is above all. (Silvia)*

Silvia's care work, like the work most caregivers do, is hard and exhausting. She has a weak financial situation, a bad health condition herself and has a small social network she can count on for support. It is tempting to predict that these circumstances would lead to a very intense experience. Some carers would indeed experience a very intense daily life under these circumstances. However, caring for her elderly mother is emotionally rewarding for Silvia.

This third part of the thesis is a journey through caregivers' lives to understand how they experience care. It unravels the investment and daily pressures of family carers of elderly parents and parents-in-law in need of care. It goes from the activities that entails care work (Chapter 5), to the context in which is embedded (Chapter 6) to finally get into deeper understanding of the intensity of the experience (Chapter 7). The analysis show that the intensity of the care experience is importantly shaped by the emotions which stem from the relations in which care is embedded, the motivations towards care and the perceptions towards the care role. The section shows that caring is not a heavy load or a joyful activity per se; its experience depends on the context, relationships and emotions (Kremer 2007). The emotions involved in the care experience, in addition and in relation to care tasks and the care context, allow a full understanding of the experience of care.

The situations of carers are diverse, complex and that the intensity of the experiences of carers does not simply relate to their daily tasks, nor to the sum of constraints and difficulties of the particular situation (although the sum of constraints and difficulties does make caregivers more vulnerable to experience intensity, a particular context is not necessarily linked to a specific experience or intensity). Situating carers' actions in their more general context including its emotional dimension allows a more complete understanding of the intensity of the care experience. Thus, Part III finds that the intensity of care is dictated by the tasks, situations and more importantly, by the emotional dimension of care, emotions that usually emerge from more subjective variables rooted in the social relations in which care is embedded.

This study approaches the intensity of care from a qualitative perspective to overcome the limitations of quantitative studies (as mentioned in Chapter 2, dedicated to the methodology). Simply calculating the number of hours spent in front of an elderly parent or tallying the tasks caregivers do daily as done in economic research or research on the 'burden of care' does not provide an accurate appraisal of the intensity of the experience as lived by the caregiver (Campéon and Le Bihan 2013). An accurate appraisal of informal care must consider the scope and impact of the investments made in terms of time, money, physical and emotional energy and the profound impact on the caregivers' relationships. It must consider that caregiving can be experienced as emotionally and morally rewarding (Campéon et al 2012). It must also consider that there are several conditions and situations that could be problematic for some caregivers but not (or less) so for others. Caring is not a heavy load or a joyful activity per se; its experience depends on the context, relationships and emotions (Kremer 2007).

These chapters adopt an exploratory qualitative approach based on interpretative sociology to study the experiences of family main caregivers in elderly care. It identifies the experiences as felt by the carers themselves. The main carer provides assistance with both daily living and instrumental activities (Howe, Schofield and Herrman 1997). In those situations in which part of the assistance is provided by externalised care, the role of the primary carer is related to the monitoring and organisation of care, rather than its direct provision (Campéon et al 2012). Family carers thus correspond to a heterogeneous category (Arskey and Glendinning 2008) involved in the provision of direct care as well as in the coordination and organisation of care.

The sample comprises 42 cases of main carers of an elderly parent or parent-in-law in need of care (i.e. daughters, daughters-in-law and sons of elders in need of care). Cases come from four municipalities of the metropolitan region of Santiago, which cover different geographic areas of the city and have a diverse sociodemographic population profile. Such sampling strategy captures a larger variety of cases in a more efficient way. Most of the cases were identified through professionals from the social and health sector in the different municipalities. The rest of the cases were gathered by snowballing among carers and through personal contacts. To ensure their anonymity, fictitious names are used in this report.[65]

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[65] The *Examen de Medicina Preventiva del Adulto Mayor* (Elderly Preventive Medical Exam, EFAM) is a yearly, free and mandatory evaluation for all the elderlies in the Chilean public health system. Using a standardised instrument, it evaluates their dependency level, measuring their ability to carry out daily and instrumental life activities. The evaluation categorises the dependent elderly into three groups: low, moderate and severe dependency. This study includes carers of elderlies with any of these three dependency levels.

The sample is not intended as a representative sample of a particular population of carers. The sample selection criterion sought to obtain a deeper understanding of the care experiences. Since parent care is a universal experience, men and women carers come from all walks of life; they are rich and poor, highly educated and uneducated, they vary in age and stage of life and stage of their caring career, some cohabit or not with the elderly parent or parent-in-law (Brody 2004).[66] This study's sample represents the myriad of elderly caregiving situations, thus including carers from different socioeconomic and age groups, working status and family situations. One or two interviews per subject were conducted. The second interview allowed deepening and clarifying issues reported during the first interview. It is of course, impossible to capture the full range of caregivers' characteristics with the sample.

Six cases are carers of an elderly parent–in-law and the rest of the cases care for an elderly parent. Only three cases are male carers, all the rest women. Nine cases combine elderly care with part-time employment, six cases with full-time employment. Eleven cases do not cohabit with the elderly they provide care, the rest all live together with the elderly. There are eight cases that belong to a high-income household, four to a high-medium income household, 19 to a middle-income household, nine to a low-medium income household and two to a low-income household. Sixteen elderly under care by caregivers in the sample are severely physically or cognitively dependent; 19 have a moderate level of dependency and 11 have a low level of dependency.[67] Twelve carers in the sample combine elderly care with care of another family member, either a grandchild, a child or a dependent sibling.

More details on the methodology (sample, instruments and analysis) are presented in Chapter 2. The Appendix VI presents a table with the main sociodemographic characteristics of the carers and Appendix VII a summary of each carers' narratives and care-related experience.

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[66] All interviewees read and signed a consent form agreeing to the use of their interview for this research's objectives (Appendix III). Names and other identifiable interviewee information have been changed to guarantee the anonymity of the subjects.

[67] This sums to 46 elderlies with different dependency levels, and not the 42 carers in the sample because there were four carers in the sample who care for two elderlies.

Chapter 5. Caregiving tasks: Diversity in the role of carers

This section describes the tasks carers carry out to provide care to their elderly parent or parent-in-law. It describes these tasks in terms of how carers experience them – as opposed to a numeric estimate of hours invested in a set of independent tasks. The section sheds light on what is involved in 'doing care'. Care is work, but, crucially to understand how caregiving tasks are experienced by carers, it is work that encompasses emotions.[68] This chapter describes the different tasks embodied in the experience of elderly care, with special attention to how caregivers feel about them. Tasks are an important first approach to understand the experience of those who provide elderly care. As will become clear, however, it is limited and does not provide for a full understanding of the caring experience. More elements beyond the tasks carried out are needed to understand where does the intensity of the care experience comes from. Though we will not understand the complete experience of care just focusing on the tasks, it is one necessary step that is complemented with other layers involving the context and the social relations and the emotions involved throughout.

The tasks performed by a family member who cares for an elderly parent are many and varied (Campéon and Le Bihan 2013). These activities can be grouped in four categories (Campéon et al 2013):

1. Instrumental tasks (help provided in activities of daily living such as cooking, laundry, cleaning, etc.) and personal assistance tasks (such as dressing, toileting, getting in and out of bed, etc.)
2. Emotional support
3. Surveillance activity
4. Organisational tasks

Caregivers in this study carried out most of these tasks, with some important gender- and income-related differences. There is a persistent division of tasks between genders, as male carers do not usually carry out personal tasks. Cases from high-socioeconomic status externalise instrumental and personal tasks to paid carers.

Some tasks were experienced as more difficult than others. Surveillance tasks, and personal tasks, in some cases, were experienced as overwhelming. Organisational tasks (e.g. setting medical appointments) posed difficulties for lower-income carers. Emotional support, although an important component in carers' experience is often not considered a caring task by carers

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[68] The support of an elderly in need of care is not only a rarely recognised form of work, but work that takes place in a specific emotional context (Le Bihan and Mallon 2017).

from lower socioeconomic households. By contrast, carers from upper-income household income are aware of their investment in emotional support.

The chapter describes the different tasks involved in doing care, presenting its main features and how they are experienced by carers.

5.1 Instrumental and personal assistance tasks

Instrumental activities include housework such as doing the laundry and cleaning, preparing meals, shopping for groceries and clothes, managing the elderly's money, administrate medicine, etc. Personal assistance tasks include helping the elderly getting in and out of bed, feeding the elderly, dressing them, toileting and/or bathing them (OECD 2013b).

Most of the interviewees provided instrumental and personal care for their elderly parent or parent-in-law, even among middle-income households where part of the caring duties were externalised. Only in high-income households, where there was a high degree of externalisation of caring duties, main caregiving daughters were not involved in the provision of personal assistant to their elderly parent or parent-in-law.

The provision of these tasks varies among gender, the elderly's health and his or her level of dependency. The more autonomous the elderly, the less he or she will require help in personal assistance tasks. At the beginning of their dependency path, instrumental tasks are among the first tasks for which elderlies need help.

Claudia is the main caregiver of her 86-year-old mother with low level of dependency. Although her mother is autonomous in many aspects of her life, she has recently started needing help with some instrumental life activities. Claudia works part-time every day as a cleaning lady. When she finishes work she visits her mother who lives 20 minutes away from her home. She helps her to clean the house; it has become too hard for her mother to do it due to the lack of autonomy associated with her advanced age. Claudia has also started to manage her mother's money, picking up her pension at the municipality and distributing it to her mother in three parts each month.

> *I usually go there after work and I help her clean the house, even if she is not at home I help her, because now there are some things that she cannot do. It is not easy for her to accept that she needs help, but I help her anyways, I guess that at the end she likes it. (Claudia)*

The main features of the experience of providing instrumental and personal assistance tasks are: a) the strong gender component in the provision of instrumental and personal care, b) instrumental tasks can be a source of respite, c) intimate care is very sensitive, d) intimate care is an exclusively female task, and, finally d) administrating medicines is an important issue in the daily routine of care.

5.1.1 A strong gender component in the provision of instrumental and personal care

There is a strong gender component in the provision of instrumental and personal care. Usually, it is daughters or daughters-in-law carrying them out. In the few cases in which female carers receive caregiving help from men (e.g. brothers or husbands) it is usually not with these tasks. Instrumental and personal care tasks are the domain of the private space and this remains a female domain in Chile. These beliefs respond to social patterns related to the skills and responsibilities attributed to each gender. In this study, as was also found by Bover and Gastalk (2005), the instrumental help offered by men who are not the primary carer was usually related to economic issues (e.g. the payments of medical treatments, or the provision of help when physical force is required, such as moving an elder from one bedroom to another, or to the car seat, etc).

In this study, in only very few cases did men carry out instrumental tasks (e.g. cleaning the elderly parent's house). These cases were all from low- or low-middle-income families. Alejandro, for example, lives with his moderately dependent elderly parents (80 and 87 years old) and his wife, Paz. They work together as 'mariachis', street singers. Paz is the main carer of her parents-in-law and Alejandro cleans the house and prepares food for his elderly parents. Also, Isabel is the sixth of nine siblings. Though her severely dependent father and her mother live with one of her brothers, she is the main carer. She visits her parents daily; her brother is in charge of cleaning the house.

For the most part, however, men – even in the unlikely event they are the main carers – do not carry out personal or instrumental tasks. Trinidad is the main carer of her severely dependent 98-year-old mother and her brother who has Parkinson's disease. Both her mother and her brother live together with another brother (the eldest), a 20-minute bus ride away. They are eight siblings. The eldest brother sometimes helps her in providing care, in the form of money or helping with tasks that require physical force when Trinidad can't anymore:

> *My brother helps me with some money and when I am exhausted and tired and I cannot do anymore I have to ask for his help because I do a lot of physical force, and with his help it is easier to move my mom in her bed, ugh you do need to do a great force every day. (Trinidad)*

Claudia speaks of a meeting in which she asked her brother for help with caring tasks. Although she is the main carer, when she thinks of the possible help she could receive from her brothers these tasks are related to culturally male-related skills, those associated with financial help, physical force help, electronic reparations in the house, etc:

> *Look, when we met the last time I just told my brother, look, these are the needs of my mom: the light (the switch) is too high, she has to use something to hit the switch to turn it on and off. Then he told me that he thinks he can help my mother with that, to bring it*

> *down to her height, because you know, elderly people become smaller in height with age... My youngest brother is the one that wants my mom to be modern, having her things, now, for example, he changed her TV, he wanted my mom to have a big TV, it is him who bought her the electric blankets, and helps repairing things, but I'm the one who is always with her. (Claudia)*

These cases resonate with the fact that the gender division present in the provision of personal and instrumental tasks is not only the image of cultural determinism for women, but it also excludes men as suitable for these tasks, obscuring they potential contribution (Bover and Gastalk 2005). Most female carers in the study assumed that their brothers' economic contribution was enough. They did not think of other ways in which men could participate and contribute to their parents' care.

5.1.2 Instrumental tasks can be a source of respite

In some cases where there was no externalisation of care, some of the instrumental and daily life tasks were seen as a source of respite among all the other daily care tasks. This was especially the case for household chores, as is true for Sara: "*when I need a rest, I do housework, it is a relief for me to do these kinds of tasks, such as cleaning the house, cleaning the toilet, just do these things helps me disconnect."* It is also true for Lucía, who disconnects and relaxes while cooking in her kitchen. She cooks not only for her family but also does pastry to sell among neighbours and at her daughter's school. Her house has the sweet smell of a bakery; she has a very nice and well-equipped kitchen. Eugenia, who spends most of her days alone with her severely dependent mother, also finds respite doing housework.

5.1.3 Intimate care is very sensitive

One of the most difficult and intimate personal assistance tasks for some family carers is body care (e.g. bathing and toileting). Twig (2000) finds that these activities "offer a rich source of implicit meaning in people's lives, sustaining and expressing relationships, endorsing values and beliefs" (Twig 2000:4). In the words of Violeta, who cares for her mother with moderate dependency: *"Do you know what is the most difficult part of my day? When I'm bathing my mother, then I get hysterical."* For Violeta, bathing her mother is the primary expression of her mother's frailty and dependency; issues that she still has trouble accepting.

Providing help with intimate care is physically demanding for daughters and daughters-in-law; it has distressing emotional overtones (Brody 2006). Silvia thinks about herself as an infant and her mother changing her own diapers when she changes her mother's. It is a very sensitive issue and emotionally disturbing for her. She cried during the interview when she referred to these intimate tasks. Seeing her parent without the ability to go to the bathroom on her own symbolises their health deterioration, which makes her sad. For Adela and Trinidad, both caring for their respectively moderate and severely dependent mothers, providing intimate care is like treating with a very fragile human being. It symbolises how much their mothers have changed in the last months and have become different persons.

5.1.4 Intimate care is an exclusively female task

Even if they are the main carers, male carers do not provide intimate care. They find help in women from their social support network to carry out these tasks. Mauricio is the main carer of his elderly mother and his sister. When it comes to his mother's intimate care, it is his sister who carries it out, even though his sister has a low level of dependency due to her health condition.

> *I am in charge of everything that a housewife does: cooking, ironing, taking care of my mom, cleaning the house… We have a portable toilet, and I put my mom in it, then my sister takes down her pants and takes her diapers out, once she pees it is my sister who cleans her. Then I get her out of the toilet and put her back in her bed or on the wheelchair. If we have to take her to the doctor it is me who puts her in the taxi, I have good technique to pick her up and sit her well. (Mauricio)*

The belief that men cannot provide intimate care also appears among carers with the financial means to externalise part of the caregiving tasks. Adela works full time and is the primary caregiver of her mother with Alzheimer's disease. While Adela is at work, a male neighbour cares for her mother under a paid arrangement. Every day, before going to work, Adela puts a diaper on her mother. Her mother stays with the same diaper the whole day, so that the male carer does not have to change it. When Adela comes home at 19h she takes out the diaper and gives her a bath. For the last few weeks, Adela's mother has started to pull out her diapers during the day. It has become a problematic situation, to the point that Adela is thinking about quitting the job she likes and needs if she does not find a trustful woman who can take care of her mother during the day.

> *I work the whole day and there is a man who takes care of my mom during the day. He is an excellent gentleman who lives in this same building; I met him through my brother. Now there are things he does not do, things related to my mom's intimacy, and this is currently a very big problem because she is not controlling sphincter and she is taking her diapers out during the day. (Adela)*

In cases where the elderly in need of care is a male, female carers provide intimate care only because the elderly wants it that way. This is the case of Isabel's and Lucy's father. Isabel's brother lives with his parents but he doesn't carry out any intimate care tasks. Lucy's son also participates in carrying out some caring tasks, but has never been involved with his grandparents' intimate care.

There is a strong cultural belief that intimate care is not male territory, to the point that a female carer, Adela, was willing to leave her job as a result. This belief was observed in cases from different socioeconomic conditions as well as among the different generations of carers and independent of the elderly's gender.

5.1.5 Administrating medicines is an important issue in the daily routine of care

A strong component of the everyday life of a carer of an elderly with moderate to severe dependency is managing medicines. As an elderly becomes older and more fragile their caring demands become more complex. This includes, notably, the administration of medicines. In Chile, elderlies are the age group with the highest medicine consumption (Arriagada et al 2008). Usually there is someone, the main carer, in charge of their administration with important effects on their daily life activities. Fátima, for example, has five daily alarms set up on her mobile phone to remind her that her mother needs to take a medicine. If ever she needs to leave home she makes sure that it's either not at a time that her mother needs to take a medicine, or that there will be someone to give the medicine to her mother in her place. Trinidad pasted the medicine schedule in the middle of her living room so that neither she, nor the morning paid carer that comes to help her, forget.

The administration of medicines is also an issue when there is externalisation of care. Main family carers are constantly buying medicines and supervising that hired carers administrate them as prescribed by doctors. It was also mentioned in some interviews that supervision is particularly important because hired carers have stolen the medications. In Chile medicines are expensive. Having them disappear can be costly for the household, requiring close supervision.

5.2 Emotional support

Beyond personal and assistance tasks, carers also provide moral and relational support to their parents. Emotional support is the most universal form of family caregiving and the one most wanted by older people from their children (Brody 2004). Emotional support means giving the elder the sense of having someone on whom to rely, someone who is interested and concerned, someone who cares, someone who listens. Emotional support can imply regular visits (if there is no cohabitation) to check on the elderly's wellbeing or to spend time together (e.g. have tea, walk, watch television, read the newspaper, play cards, etc.). Emotional support is also provided when the elderly needs a companion (e.g. going to another family member's dinner or spend vacations together).

Emotional support is rendered to the elderly parent or parent-in-law on a daily and constant basis. The provision of emotional support cannot be quantified and is probably underestimated with respect to the time and effort consumed (Brody 2004). Indeed, carers themselves often underestimate it (Campéon et al 2012). For this reason, quantitative studies measuring the intensity of care by the time spent providing care ignore the hours providing emotional care.

When carers – especially those who also provide instrumental and personal assistant tasks – talk about their caring tasks, they rarely mention the fact that they provide emotional support as part of their caring duties. Yet, when the same carers talk about their daily life it becomes clear that emotional support is constantly present in their discourses:

> *In the afternoons I accompany her, I take her outside because we live next to a square, but if suddenly she does not want to walk anymore I sit with her a little bit outside. If it is cold, then we watch television together. (María)*

Pedro's mother, an elderly women with cognitive and physical dependency, is constantly asking her son for emotional support. She wants him to give her company and stay close to her. When Pedro arrives from work, at 19h every weekday, his mother looks at him, stretching out her hands ands ask him to take her hands between his.

> *All she wants is that we sit close to her, to give her physical affection, for example, to hold her hands. She asks me to sit by her side. Other times you unconsciously take a chair and sit by her side. She is always looking for your hand; she takes your hand and holds it. (Pedro)*

The effort and difficulties involved in providing emotional support to a parent or parent-in-law can be considerable (Brody 2004). Spending time with the elderly parent accompanying him or her can become a difficult task. Sometimes the carer prefers to avoid it, especially when they feel that the elder is not in a good mood or when they do not have a good relationship with them.

> *When I have time, I stay with him, and I sit down close to him and I give him company him and we chat while eating. I try not to leave him alone for too long, but sometimes I struggle and I can't because some days he is unbearable and everything is a matter of discussion 'I do not like this, I do not like that, that this little girl [her daughter] is spoiled'. So instead of accompanying him to discuss, I prefer to eat alone. (Lucía)*

Cintia is her mother-in-law's main carer; Ana María her mother's. Both carers have elderlies with a cognitive dependency who live in a nursing home. They spend most of their caregiving time providing emotional support and company. Cintia (65 years old) is comfortable with her mother-in-law's care arrangement and her own role as an emotional support provider. She enjoys going to the nursing home and chat with the staff members, whom she knows for more than ten years as her own mother also lived there. As Cintia is retired, she doesn't feel that rushed to get to the nursing home; she doesn't feel she doesn't have enough time to spend there, as she felt when her mother was there. Ana María (63 years-old), by contrast, gets bored when she visits her mother. She doesn't like the fact that they cannot keep a conversation as they used to in the past because of her mother's cognitive deterioration. Ana María tries to use her time at the residency in a 'productive way', like answering her emails or making phone calls. Most of the time, she just plays computer games.

> *Instead of enjoying visiting her, I am more and more by her side not looking at her but answering emails or phone calls, there are more and more days that I go there and I only play domino in the computer because in reality there is not much I can talk with her. (Ana María)*

5.3 Surveillance

> *For me it's not the physical tiredness the heaviest [task], but the tiredness of thinking about them the whole day, thinking whether they are well. I don't know, that's the heaviest [source of] pressure for me. (Lucy)*

Surveillance is an activity associated to caregiving that, like emotional support, is not associated with a direct or hands-on provision of care. Surveillance can be a constant concern for the carer and, in most cases, experienced as a difficult task.

Eugenia mentions how she is always vigilant of her severely dependent mother at home, even if she is not providing direct care and doing something else. She is concerned when she has to leave the house and cannot keep an eye on her mother – even if she leaves the house only rarely.

> *[For me,] my mother comes ahead of anything, after finishing with her in the mornings I start cooking and cleaning the house. However, I have to be aware of her all the time because she has some respiratory problems. One day, she had a respiratory failure; the crisis began when I was giving her breakfast. So for me it's hard because I have to be checking if she is all right all the time, and if I ever have to go somewhere else I have to go running. I have almost been hit by a car twice [because of this]. (Eugenia)*

Surveillance means that carers have to remain close to the elderly. Carers have to be able to respond immediately to any need that the elderly parent or parent-in-law could have:

> *Caring for my parent is mostly just being attentive to their needs, it is not that I have to spend the whole day doing things for them. For example, my dad gets out of bed alone, then I wash his teeth, I give him breakfast, and that's it, and mom changes her diapers herself, it was a task she learned to do when I was away from home working on the north of the country. (Lucy)*
>
> *One must be alert all the time, alert because sometimes, while she is walking, the dog can cut her path and she can fall, when she is in bed, one must verify she has changed positions so she doesn't get bedsores, attentive in case she wants to go to the toilet, it's like having a small child. (Violeta)*

This surveillance task can become a major difficulty if the carer can't be physically present all the time and the elderly's dependency level is moderate to high or if the elderly has cognitive dependency. Carers mentioned that they have to run everywhere posing a major difficulty to their every day lives. Silvia is the primary carer of her mother, they both live together and whenever Silvia has to go out to buy bread, to get her mom's pension or to buy some groceries, she is constantly worried because she cannot provide surveillance to her mother.

> *In fact, when I have to go somewhere, I am only thinking on the time to come back home, because I am worried that something could happen to my mom. (Silvia)*

Carers who do not live with the elderly parent or parent-in-law in the same house are also often worried that something could happen to them while they are alone. In fact, most of the decisions towards cohabitation take place when the elderly becomes fragile. The family thinks they need closer surveillance and choose cohabitation because they either do not have the means to externalise surveillance or don't think on externalising as a possibility at all. Carers who leave their elderly parents alone while they go to work highlight the burden that causes them the fact that their parents are not surveyed for a large part of the day, as is the case for Ofelia, Colomba and Francisca. These three carers call their parents by phone several times a day to make sure they are all right. If they don't answer, they call a neighbour with whom they have good relations to check.

5.4 Organisation and management of care

A final series of tasks are related to monitoring the elderly's health status and organising their daily care. Such tasks can entail a bureaucratic burden (Campéon et al 2013).

This organisation and management of care usually starts when the elderly begins needing care. It can also follow a hospitalisation, illness or the death of the spouse. Whether progressive or urgent, a first task corresponds to the organisation of the care arrangement. It means bringing siblings and other family members together, distributing tasks and resources among the family, discussing care-related preferences and agreeing to them, organising each member's involvement, schedules and specific tasks, etc. (Campéon et al 2012). For the elder and the family these management tasks and discussions may be completely new. Management tasks are not a one-time effort; it is an on-going task, as even the most careful arrangements break down from time to time as the elderly and their family's conditions and needs change (Brody 2004).

Carers who externalise some caregiving tasks must orchestrate this externalisation. They must make sure that these externalised tasks are effectively carried out (Campéon et al 2013). For example, an in-home paid worker may fail to show up on time or to arrive at all, enticing a series of unexpected activities to make sure care is provided (Brody 2004). Carers who do not carry out direct care activities are still invested in care by taking on the role of care manager (Da Roit and Le Bihan 2009, 2010). The management role is time consuming and sometimes frustrating (Brody 2004).

While the existence of public support and an extended support network may relieve carers from certain tasks, it also creates a new task in managing this support. This is particularly the case in European countries where the government has assumed some degree of responsibility in elderly care. Among carers who take advantage of the possibility to externalise care in public services, the organisational and management tasks become important (Da Roit and Le Bihan 2010). While this may be less so the case in Chile because care usually relies in only one family member (opportunities for public support are less prominent in Chile and the possibility of externalising care is rare), management still is an important caregiving task.

Among households that externalise part of the caregiving tasks, the organisation and management of the elderly care was always mentioned as an important caregiving component. Externalisation of care is a solution for decreasing the caring tasks but it does not necessarily reduce the care responsibilities (Campéon and Le Bihan 2013).

Consuelo is the main carer of both her parents-in-law (one with severe physical and cognitive dependency, the other with moderate physical dependency). She lives with both parents-in-law and has an external carer on weekdays from 8h30 to 18h. Organisational and management tasks are predominant in her role as main carer. They overwhelm her. She needs to coordinate with her sisters-in-law who will provide elderly care on those days in which the external carer does not work and Consuelo needs some to care for her parents-in-law so she can go to work.

For Elisa organisational and management tasks are not a difficulty. She lives with her mother-in-law, who has a low level of dependency, and has a paid person living in her house who takes care of her mother's personal needs 24 hours a day. For Elisa, the organisation and management is the predominant activity in her role as carer. She sees it as one more responsibility in her caregiving agenda.

> *For me, responsibility for my mother-in-law's care does not change my life very much. Any doctor's appointment or any other activity that concerns her care is scheduled in my agenda as one more activity within all the activities I have to carry out for my seven children. (Elisa)*

These two women from high middle-income households experience a similar organisation and management of care in different ways. To understand why a similar arrangement can lead to different experiences it is necessary to account for their individual and broader context. This includes, among others, the perceptions towards their role as carers, the reasons why they became carers, their relationship with the elderly and other relatives and their biography. The discussions in the following chapters unveil carers' context and other relevant elements to understand their specific experience.

Main features of the organisation and management of care that pose difficulties to some carers are a) supervising paid carers, b) managing conflicts between nurses and domestic service, c) managing the elder's own home and d) setting appointments with health professionals.

5.4.1 Supervising paid carers

The presence of formal carers can add pressure to the care experience (Soulier 2012). It implies new actors and a new challenge of organisational management for the carer. Formal carers imply opening the elderly's home to non-members, generating a sense of loss of control of the process of care, greater insecurity and a feeling of pressure (García 2010).

Among high-income households, the organisation and management of the paid carers is among the most complicated and demanding tasks for the main carer. Marita is 79 years old and lives with her severely dependent 103-year-old mother. Marita's mother had a heart attack, which led to a three-week hospitalisation eight years ago. Upon discharge, her two daughters and two sons decided that she could no longer live alone and she went to live with a son and a daughter-in-law before living with Marita, her eldest daughter. During these eight years, they have hired external carers for their mother's care. In the beginning, they hired formally educated nurses from a specialised company. Marita found they were paying for technical knowledge that was not necessary because, back then, her mother didn't require complex care. Moreover, the dispatched nurse changed almost every day. A system with such rotation did not offer any emotional support and made it seem like the carers were strangers in her house. Marita did not feel completely safe with her mother and the house alone with a different nurse every other day.

In order to find a more stable and closer service, Marita and her siblings decided to hire an older woman who provided domestic service in the past to one of the sisters. This woman already knew their mother. The new full time carer was originally from Peru, as have all those they have hired since then. Marita is satisfied with the work these women have done and preferred them to the professional nurses.

However, for Marita one of the most difficult parts of being her mother's main carer is what she calls the 'externalisation issue'.

> *[It] limits my life in many aspects, but look, everything has a good and a bad side. Now I have less freedom to move and to do my own things because I have to be watching for carers closely every time a new one arrives because it's not that I can leave them alone right away when they arrive. (Marita)*

She also refers to the worry she feels every time a hired carer announces she is leaving, something that has happened often with the Peruvian women they have hired.

> *…then I hired another Peruvian woman so she can help with the house chores because the one who was caring for my mother was having too much work to do. This new woman was an aunt of my mom's carer, both of them from Peru. Then the one dedicated to the caring duties became pregnant and left on this 'famous prenatal leave' and left us with another women from Peru who was recommended because she had previously taken care of an elderly in Peru before coming to Chile. A month ago she had some health problems and wanted to go back to Peru to get treatment close to her relatives. Before she left she recommended another Peruvian women and she taught this woman a little bit how to care for my mom. It was supposed to be a replacement that was going to last until she came back from Peru [after treatment], but she called me a few days ago saying that she was not feeling good and decided to stay in Peru and is not coming*

> *back. Thanks God the other woman told me that she could stay with us. Then we also have a woman that comes from Friday to Sunday to stay with my mom, while the person who is here during the week does not work. (Marita)*

5.4.2 Managing conflicts between nurses and domestic service

Some high-income families decide to have their elderly parents living in their own home and hire nurses to take care of part of the caring duties. These households usually have had domestic service for much longer than the elder has become physically or cognitively dependent. Rebeca, Josefina and Aurora (high income main carers of elderly parents in need of care), mentioned that the management of human relations between their parents' careres and the domestic service was a complicated issue.

Josefina is 65 years old and is the main carer of both her father (94 years old) and her mother (91). Both have physical and psychological dependency. Nurses provide direct care for her parents. The remaining caring tasks are covered among the four siblings, coordinated by Josefina. For the last five years ago her parents need care day and night, "*five years that have been eternal and very heavy,"* says Josefina. The two things that she found most difficult are the organisation and management of externalised care and the organisation of the house after years in which it had been her mother's responsibility.

> *It became like a sick system with all these nurses who are terror itself. The truth is that the nursing system in Chile is horrible. First there is a social thing, the nurse feels superior to the domestic service and is always making a difference. The maid has been working for my parents for 20 years and when suddenly she doesn't have her bosses any more, a horrific antagonism between the domestic service and the nurses began to grow. Nurses are so poorly trained, poorly controlled; I'm talking about home nurses… The general training of a nurse is very, very poor, both in geriatrics and in human relations, especially with a tough attitude to live in a family home… The maid was so mad with the nurses that we realised she was just cooking spaghettis every day, until I noticed and talked to her. (Josefina)*

The effect of the externalisation of care on the care experience depends on whether it is considered a well-deserved respite for the carer or a response to a lack of commitment (García 2010). No case in the study externalised part of the caring duties and mentioned feeling upset because they were delegating their responsibilities in other people's hands. No carer from the sample mentioned that they felt guilty or irresponsible for delegating part of their elderly parent's care. However, those cases that do not externalise care mentioned that even if they had the resources they wouldn't do it. This issue is discussed further in a forthcoming section.

5.4.3 Managing the elder's own home

At some point in the dependency path, elderlies are no longer able to take care of all their house's issues. At this point, some tasks need to be left to others, or, at the very least, the elder needs to receive help to carry them out.

For some high-income families who decided to leave their parents in their own home, it was difficult to find the right moment to take control of the elderlies' house management. This is because the elderly's dependency path was slowly progressing, because the family did not want to assume the dependency or because it was too difficult to take in the new management responsibility. The latter was the case for Josefina.

> *There is an important issue in this type of organisation when parents stay at home. On what minute do you take charge of the house management and you take your mother out, she, who was the original hostess of the house. This is a very difficult transition and finding the right moment and intensity to get in was not obvious, when was the right moment to leave her totally out? [For us] this transition was very bad and we waited too long. [My parents] were eating badly and their house was a mess. But today we do the shopping and we follow the advice of nutritionists; we manage the domestic service. So good it is now more organised… (Josefina)*

Aurora is her severely physically dependent mother's main carer. Her mother lives in her own place with a nurse and a maid. Aurora manages all of her mother's care, including all domestic issues, which were under her mother's responsibility until she lost her physical autonomy. Her mother is aware and upset of this change in the management responsibility, upsetting Aurora as well.

> *She still wants to control all the aspects of the house, because her head is perfectly working, but physically she really cannot do anything and it has been very hard for her to give up her original responsibilities. It is distressing and it makes me very sad. (Aurora)*

Low- and middle-income family members who decided to move to the elderlies' home as the latter needed care also experience these difficulties. Those who had been living with their parents for years and have begun taking a more dominant role in the household administration also experience these difficulties. They tend to adopt a more dominant role in the household administration because the elderly parent is no longer able to manage the house or the carer believes they are no longer able to do it. Lucy has always lived with her son in her parent's house. Her father has Alzheimer's and her mother a physical dependency. Lucy describes her family model as a matriarchy. Today, that model only persists in symbolism, because Lucy is completely in charge of all house matters. Her mother, however, still wants to control everything and Lucy feels that pressure.

> *My mom decided to sleep here, in the middle of the living room, and spends 24 hours a day here, on the same sofa. For more than a year she hasn't used her bed* (located in a

> bedroom in the second floor). *I think she wants to be attentive to everything that happens here, as if with the inability to walk she loses control of certain things that she used to control before. So being here in the living room, which is at the entrance of the house and next to the kitchen and the dining room, she can see who comes in and who goes out and everything that is going on down here. (Lucy)*

5.4.4 Setting appointments with health professionals

Making appointments with doctors and health practitioners and being in direct relationship with the health practitioners or social services is another important organisation and managerial task for carers. Family carers are often called to serve as advocates for their parents with health care professionals (Neufeld et al 2008), a role that can create further tension and fatigue for the carer (Willyard et al 2008). Obtaining an appointment with the doctor for an elderly in the Chilean public health system requires going directly to the health centre (with the exception of severely dependent elderly who are part of the domestic care programme from the Health Ministry and receive health professional visits at their residence). This means that carers have to wake up before 6h in the morning so they can be in the health centre at 6h to stand the line to get a number. They are called by order of arrival to set up a medical appointment for the elderly. This also means that carers will have to come back to the health centre with the elderly on the day of the appointment (only elderlies with severe dependency receive home visits and do not have to follow the same procedures to get an appointment, their carers can make them by phone).

This arrangement brings difficulties for carers. They either have to organise all their family life before leaving that morning (without much clarity on when they will be back) or they have to leave the elderly alone for some hours. Rodrigo, the main carer of her moderately dependent mother, lives with his mother and no one else in the apartment, located in a middle-income neighbourhood. He is 70 years old; his mother is 92. Rodrigo manages all his mother's medical appointments. Whenever he needs to set an appointment for her, he wakes up between 4h and 5h so he can be at the health centre at 6h. Once he gets the date for the appointment, he has to take his mother to the health centre, with the difficulties associated to taking two buses with an elderly mother without physical autonomy.

> *I have to wake up certain days before six o'clock because you need to get a number in the primary health centre to make the appointment with the doctor. To make an appointment for medical exams I must be there with my mom at 8h. Last week, I went to the primary health centre because I had to make an appointment for her with the ophthalmologist. I should have done it two months ago, and I also I have to make an appointment with a neurologist, but as I say I have to be there at six o'clock, take a number and then they tell me I have an appointment on what day and hour with Dr. X, so that day I have to go with her, but as I told you when I have to go alone to make the appointment and be there at 6h I wake up at four or five to be there at six. That is the normal, if you arrive at six o'clock there are already 20 people waiting [in line]. (Rodrigo)*

Fátima, a 46 year-old woman, is the main carer of her 85-year-old moderately dependent mother. They live in Fátima's house, with Fátima's husband and four school-age children. She wakes up ever day at 6h to prepare breakfast and arrange her kids to go to school. After a normal day she is always very tired, but even more so the morning she has to go to the primary health centre to set up an appointment with her mother's doctor or when she has to take her mother to the primary health centre.

> *Oh God, those days that I have to go to the primary health centre for my mom's appointments are chaotic, my home is always a mess those mornings and I have to start the day before [the usual time]. And so at night, those days, more than any other days, I'm dead tired. (Fátima)*

The relationship with the elderly's health care professionals is often an individual task. It is often carried out by the main carer alone, or by one sibling who has taken responsibility for the medical and health issues but without the involvement of the other family members. From the study participants from low- and low middle-income families, only few cases mentioned that they met with their siblings to discuss about their parent's health needs and health care. Only when the elderly experiences major health events the main carer informs relatives about this, but not to discuss future steps of the health care procedures; there is no associated decision planning.

As an exception, in three families there was discussion among the siblings about the elderly's medical care. In these cases one of the siblings was in charge of the medical issues and he/she communicates, or not, with the rest of the siblings about them. Penélope calls herself the 'health manager' of her elderly parents, she has one sister and two brothers; her mother has cognitive and physical dependency and her father a low level of physical dependency. She lives in Santiago and both her parents in Curicó (around 300 kms. south of Santiago). She sets up the doctor and other health professional appointments. Whenever her parents have to visit a doctor they come to Santiago. She picks them up at the bus station and takes them to the doctor, she buys medicines and organises them to make sure her parents take them.

> *Last month my mom was hospitalised and as she has Alzheimer's I have to stay with her during the night, otherwise she wakes up and feels lost. Then, during the day my dad stayed with her while I went to work. There are things that I talk with my brothers regarding my parents' health status and care, but there are several others, maybe of minor importance that I only communicate with my sister, things that may be taken as obvious, and tasks that we attribute to ourselves because we are women. My brothers' contribution is mainly on the economic side. The health management is under my whole responsibility, the domestic issues under my sister's and between both of us there is usually a good channel of communication and we usually make the decisions together. (Penélope)*

5.5 Conclusions

Caregiving tasks are diverse and vary along carers' and elderlies' profiles. Some pose difficulties for some carers, some are neutral and others are seen as respite. For some carers the most difficult tasks are related to the elderlies' personal and intimate care because of the physical demands but also, and perhaps more importantly because of the suffering involved with assuming their parent's dependency. Cooking, cleaning and doing the laundry are in some cases experienced as a respite from the direct caring activities. The surveillance task is a constant source of difficulty both for the carers who cohabit with the elderly and for carers who have their parents with low dependency level still living alone and without external help. The organisation and management tasks are one of the main tasks performed by high-income carers. The management of the external carers can be a source of difficulties. The organisational tasks among the low and middle-income families, who barely externalise any of the caring duties, involve dealing with the health system: setting up appointments with doctors and health practitioners. In most low-income and middle-income families the same main carer carries out all the caring tasks. In high-income families personal assistance tasks and some instrumental tasks were usually externalised. The role of other family members was usually associated to the management and organisation of care. It was more common to see siblings of the main carer taking responsibility for managerial tasks among the middle- and higher-income families rather than the lower ones.

As shown above, rendering care to an elderly parent or parent-in-law is a hard work. Care-related tasks are energy-demanding and usually leaves carers exhausted at the end of the day. Notwithstanding the objective exhaustion associated to care, caregivers experience the elderly care daily tasks and responsibilities differently. There are patterns regarding the tasks rendered related to the gender of the caregiver and to their socioeconomic status. But gender and socioeconomic status does not explain why some carers experience caring tasks with more or less intensity. For example, why is it that Violeta gets hysterical when she bathes her mother? Why is it that Elisa, who manages her elderly mother-in-law's caring needs along with the needs of her seven underage children is not overwhelmed?

This chapter provided a comprehensive picture of what entails caring for an elderly parent or parent-in-law from the perspective of the specific tasks involved. It is a necessary and important first approach to understand the experience of caregivers. Caring tasks are the most readily identified (James 1992) and provide a good starting point in analysing the care experience. However, care does not take place in isolation and given the emotional and relational nature of care, the care experience cannot be understood solely in terms of the set of tasks involved.

To understand the intensity of the caring experience we need to go further. The next chapter provides a comprehensive look at the context where care takes place, offering a more nuanced – yet still incomplete – understanding of the factors that determines caregivers’ intensity in their experience.

Chapter 6. The context of care: Diverse situations for carers

This chapter describes the different situations in carers' lives that need to be considered in addition to their caregiving tasks when understanding their experience of care. Situations are the social and economic conditions and context where the care experience takes place; they include the constraints and difficulties carers face. Depending on the situation, carers may be subject to stronger or weaker situations of constraints. Situations lie in three separate registers: i) those associated to the carer and the peculiarities of his or her situation (e.g. the economic conditions of carers, carers' own advanced age, multiple caring demands, etc.); ii) those directly associated to the elderly person (e.g. the level of dependency and the nature of the pathology); and iii) the organisational situations or those related to the informal support and the medical and social offer of services (Campéon and Le Bihan 2013). This chapter shows that the spectrum of carers' situations is large. Though important in understanding caregivers' experience, similar situations are not experienced in the same way by different carers; similar situations can lead to different experiences.

This chapter will first touch upon the personal and economic characteristics of the carer, it will then explore the elderly's condition and the support received from social networks and public services to identify the situations that can become constraints or resources for carers. While this chapter explores carers' context, the following will delve into the emotional, non-objective, dimension to to understand why the same caregiving and contextual situation can lead to different intensities of the care experience. Indeed, while the context offers a more precise picture of caregivers' experience and can generate pressure to caregivers, to fully understand the intensity of the care experience, it is necessary to go beyond caregiving tasks and specific situations. It is necessary to consider more subjective aspects of carers' lives including carers' emotions and relationships (Le Bihan, Martin and Campéon 2013).

6.1 The economic constraints of carers

Economic conditions are among the most vital and objective factors affecting family carers' experience (Brody 1996). Caring for an elderly parent can have considerable financial implications because of the everyday care costs, the cost of treating physical and mental ill-health, and as a result of the lost or reduced employment opportunities for carers (Cid and Prieto 2012). If elders have no right to a pension (or a very low one as is the case of most Chileans), their own care cannot be paid for. Caregiving can, in turn, imply diminished financial security and retirement savings and increase the risk of present and future poverty (Bittman et al 2004).

Financial constraints are a major issue for Chilean elderly carers. The majority of carers does not receive a formal salary, does not receive financial assistance from the social security system and, in many cases, carers do not count with the financial support of other family members (Arroyo 2010).

A direct implication of Chile’s high out-of-pocket health care expenditure and low pensions discussed in Chapter 4 is that the presence of an elderly in need of care in the household results in decreased available funds (Cid and Prieto 2012, OECD 2015a, 2015b). In most cases, care-related expenses are not covered by the elders’ pensions or not completely covered by health insurance schemes (OECD 2015a, 2015b).[69] In Chile, as in other familialistic care regimes, the direct and indirect economic demands of caregiving can be a significant cause of family impoverishment (Lloyd-Sherlock 2014).

A bad financial situation is one of the most objective constraints experienced by carers. For high-income carers, money is not an issue; for low-income carers it is a major and objective source of pressure.

Results from this study show that economic constraints stem from a) the difficulty to combine a paid activity with care work – because i) there is a lack of motivation to seek employment and ii) there is a lack of job opportunities compatible with caregiving-; b) care for an elderly family member is unpaid work, and c) elderly pensions are generally low and do not cover the expense of care.

The following sections will delve onto the causes of financial constraints and how carers experience these situations.

6.1.1 The difficulty of combining a paid activity with care work

From a purely economic standpoint, for most carers in Chile the cost of leaving the dependent members of their family under the care of other people to earn a salary would not allow them to compensate for the costs of externalising care. In other words, in the present, having a paid activity is not worth it for most carers though it carries significantly higher risks for long-term employment scarring effects and old-age poverty as a result of being out of the labour force and not saving for retirement (Krogh et al 2009).

Many carers of elderly parents or parents-in-law face increased economic difficulties because they cannot combine a paid activity with their caregiving tasks. In Chile, the main hindrance to women's labour participation is care for dependent family members (child, elderly or other). It hinders the possibility for families to improve their economic situation and exit poverty (Acosta

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[69] In Chile, the average monthly income coming from elderly and retirement pensions for the elderly amounts to 173,244 Chilean pesos per month (the equivalent of less than 250 euros) (CASEN 2011)

2009). As underlined in Chapter 3, the majority of elderly carers in Chile are between 35 and 54 years old and in their most productive age. Yet, 72% of the elderly carers in Chile do not combine caregiving with paid work (SENAMA 2009b). Almost half of women caring for a dependent person (but not their children) living in Chilean urban areas declared that caregiving limited their paid work opportunities. This restriction is strongest among low-income households (Comunidad Mujer 2012).

This study's cases follow this pattern: 24 of the 42 carers did not have a paid job during the period in which they provided care for their elderly parent or parent-in-law; 13 of these 24 said that they did not have a paid job because of their caring duties while the remaining 11 non-working carers were retired. Of the 14 carers who worked prior to their elderly parent becoming dependent, seven quit their jobs to dedicate themselves fully to their parent's needs.

Mauricio, 54 years old, faces important economic constraints because he cannot combine caring with a formal job. Caring for his dependent mother and dependent sister occupy all his time. He provides care by himself because he can't pay for external care. For him, the lack of economic means is the most difficult part of his situation and is the main cause of most of the difficulties he faces.

> *I am not working now because I am dedicated 24 hours a day to my mom. We live with her pension, a basic solidarity pension, and my sister's handicap pension, both of which total 180,000 pesos a month (approximately 260 euros). At the beginning there was no problem because other people, mostly friends, helped us, but with time that help disappeared... The economic situation is the most difficult, the most complicated part of this situation, because you still receive the electricity bill every month, you need to pay the telephone, you must get dressed, eat, pay the gas, buy bread, all those things, but you are no longer receiving a salary. (Mauricio)*

Florencia's mother first lived in a nursing home when first diagnosed with Alzheimer's disease. The cost of the nursing home, in addition to the medicines and Florencia's transportation costs to visiting her mother added up to more than Florencia's salary. She quit after a few months and decided to live with her mother and provide care full time. Florencia's household income was reduced to her mother's pension and her dead father's alimony (a household income of 270,000 pesos, or approximately 385 euros a month). This new pension-based income was more or less equal to what she received after discounting for the costs of the nursing home. But having exited the labour market and discontinued her career, Florencia will face higher risks of old-age poverty than before.

Sara worked as an elderly paid carer prior to her mother's hospitalisation. Upon discharge from the hospital, her mother began needing help with daily activities, and Sara stopped working to dedicate herself to her mother's care. Her salary was not sufficient to pay someone else to care for her mom.

> *I had to stop working. I was a paid carer for elderly people before. I was caring for an old lady, Mrs. Adriana. I worked with her for five years; her husband had died and she was 91 years old. When my mother got sick I had to leave Mrs. Adriana to stay the whole day with my mom. I did it because what I earned with Mrs. Adriana was not enough to pay someone else to take care of my mom. (Sara)*

The fact that most elderly carers do not combine a paid activity with caring work is one of the major causes of their financial impoverishment. This, in turn, increases the social inequalities emanating from care and further exacerbates gender inequalities. What is it, then, that prevents caregivers to go and seek for a paid employment?

Lack of motivation to seek employment

The lack of employment opportunities that could pay for part of care is not the only reason why women carers remain out of the labour market and experience the associated economic constraints. This is the case of Silvia, María and Sandra, who all care for their respective mothers with moderate or severe dependency, and of Isabel who cares for her father with severe dependency. For these four women, they wouldn't take a job even if it allowed them to pay someone else to help them with care duties. For them, being out of the labour force is a result of motivation associated to their perception as carers: they prefer to be their parents' or parent-in-laws' carers.

> *What happens is that if I do not care for my mom, no one will do it as well as I do it... It wouldn't be the same if someone else takes care of her, she wouldn't last long because it is not the same care that she receives from me than the one she could receive from someone else...I consider myself very apprehensive with her. (María)*

The existence of a lack of motivation to combine paid work and care in Chile is confirmed with the quantitative data of a study conducted by the non-governmental organisation Comunidad Mujer that shows that only 36% of the Chilean women caring for a dependent relative (not her children) would like to be active in the labour market (Comunidad Mujer 2012).

In their discourses, most carers from lower income households did not mention the lack of money as an impediment to externalise part of caring duties. For many carers facing economic difficulties they think that no one else could provide care as well as they do it.

> *Even if I had the money to pay someone else to help me I would never do it. I couldn't leave my mom with someone I didn't know or trust. (Sandra)*

Yet, carers with the economic means to externalise part of the caring duties, do not question whether they should have external help. They neither question combining work with caring for elderly parents. Consuelo, Adela, Pedro and Penélope, all from middle-income households, never mentioned mistrust when externalising care. Similarly, they did not feel guilty about not rendering care the whole day.

The contrast between the work-and-care combination among low-income and middle-income households brings up the hypothesis that there are different care ideals across social classes. Care ideals are conceptions of what is appropriate care (Kremer 2007). This care ideal interferes with labour market participation, potentially aggravating economic constraints for low-income households. This hypothesis bears some evidence in that there is a big gap in employment across social classes: one in every four women from the most economically disadvantaged quintile in Chile have a paid job, while half of women in the upper quintile do (Novella et al 2015). Women's perceptions of their role as family carers play an important role in explaining their low labour force participation. Perceptions towards the caregiving role are a more important factor than educational attainment or age in explaining women's labour participation (Contreras et al 2012).

The ideals of what appropriate care is are an important component in understanding carers' experience (and its variation across socioeconomic status and gender). The care ideals across cases from different economic status will be developed further in Chapter 7 as they relate to how most of the potential constraints of carers are experienced differently among carers. Yet ideals of care are also important to consider here because they explain the carers' motivation to have a paid job and combine work with care.

Some low-income carers, such as Silvia, do not even question their carer role. Silvia never thinks of combining caregiving with a paid job. Non-working low-income carers expressed that they care full time for their elderly parent or parent-in-law because it is what they should do, because they want to give back to them, because they love them, because it is the way that things should be or because they expect their own daughters or sons to follow their example and care for them in the future.

These beliefs prevent carers from taking on paid work and increase the likelihood that they will experience financial constraints. However, although care ideals differ by socioeconomic status and they prevent carers for taking on a paid job, it is also important to consider that these beliefs take place under a familialistic care regime. It is possible that more women would be able to combine care work with a paid activity if the government played a more active role in supporting women to access external caregivers or through conciliation policies. It is possible that, in a scenario with conciliation policies and/or accessible care services, low-income carers would have different care ideals and would be more willing to combine a paid job with their caregiving work.

In this line, Martin (2015) argues that (large) family solidarity or protection to relatives, as those present in *unsupported familialism* schemes like the one in Chile, is the result of the absence of government support. Without government support, families are *forced and required* to assume caring responsibilities. They *have to do so* as there isn't any real alternative. This would also explain the high poverty levels in countries under this care regime. Family solidarity is not a way to reduce inequalities, but rather a factor that increases them (Martin 2015).[70]

Low self-confidence is another factor explaining the lack of motivation that caregivers (usually from low- and low-middle-income households) have to combine caring tasks with a paid activity. Even though these carers may face important financial constraints, they do not seek employment to improve their financial situation. This is Eugenia's case, as it is for other female carers who have been out of the labour market for a long period of time.

Five years ago, Eugenia began living with and caring for her 91-year-old mother. Before, she stayed home caring for her own children for 18 years, starting when her eldest daughter was born, 23 years ago.

> *I had my daughter and stopped working. Then I tried to work for one year or so, but I thought about the pros and cons of that and no, for me it was better to care for my children. Then I became a stay-at-home mom forever. (Eugenia)*

Eugenia's children are now adults. While she recognizes that she would like to work for at least a couple of hours a day, she feels that her mental capacity does not offer any value in the labour market, possibly because she hasn't been in the job market for many years or because she is extremely tired as a result of caring duties.

> *I would like to work, eventually, maybe, but you know, the fact of being here with my mom, one becomes dumb, you lose… mmm… for example I used to have a good vocabulary, suddenly I forget the words, I used to have good spelling, suddenly I forget how words are written, I have misspellings and I am concerned, I have been losing my memory and now I forget things and that scares me, but I think it's just because I am tired. I like reading, but I also left that because I did not have time. (Eugenia)*

Lack of job opportunities compatible with caregiving

Another source of carers' economic constraints is the lack of opportunities that allow carers to combine work and care. Bringing people into the labour market is the result of workers' motivation, but also the result of available employment opportunities (OECD 2015b). For female carers, the lack of flexible employment opportunities is a barrier to labour participation. These include non-precarious opportunities in terms of part-time jobs, or jobs offering flexible hours or flexibility in the location of work. Alejandra is eager to find a part-time job that would allow her to spend some time with her elderly parent and earn some money. She used to work full time as a salesperson for a big shop. She quit when her father began having dementia and

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[70] Martin (2015) argues that the strong family solidarity present in countries with unsupported familialism care regime is not a cultural nexus of protection in the sense that people develop a peculiar sense of family and mutual solidarity based on legal obligations within the kinship. On the contrary, he argues that it is more appropriate to consider that family solidarity is the result of the political configuration in these countries.

her employers didn't allow her to change to a part time or flexible schedule. She would love to be able to combine her caring duties with a part-time job, but it hasn't been that easy to find that combination.

> *I would love to work but unfortunately this is super hard because it is hard to find a part-time job that doesn't pay a crumb, it is either that or working all week with one day off per week, or two Sundays off per month. I need to work because I have to help my husband since our economic situation has turned from grey to black. (Alejandra)*

Victoria cares for her mother-in-law and used to hold multiple jobs before becoming her carer. She stopped working after her mother-in-law's dependency level increased and none of her employers allowed her to combine work and care. Her household needs a supplemental income source and she began searching for a part-time job as she did not want to leave her mother-in-law alone all day. She had some interviews but without any success; none of the possible employees accepted that she work less than a full working day. It has been almost a year since she began looking for a job that could allow her to combine a paid activity with care work.

> *We need that I go to work again, but the idea is that if I get a job it is a job where I do not have to worry about anything. I couldn't face a stressful job right now, as I could when I was 20 years old. Now I have to deal also with my carer role. When I was working with sewing machines at the beginning of my mother-in-law's dependency, I was also extremely stressed, working too much, feeling tired… I had to get up at 7h and continue sewing until 1h or 2h in the morning. If there were unforeseen issues with my mother-in-law or if there were visitors it was horrible because they took my time and then I went to bed even later.*
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> *My husband is the only one working; he is the only one that brings money to the house, besides my mother-in-law's basic solidarity pension. But the household income is clearly short for us. The problem is that Guillermo [her husband] works as a salesman and earns depending on what he sells, so there are months that go well and others that go bad, and then there is no money and we struggle. When I worked, I earned around 260 [thousand Chilean pesos, approximately 370 euros], it was not a big deal, but we knew that we had that every month. Now I actually talked to her [her mother-in-law] because I have to work again. Now that my mother-in-law is more stable and doing better, and we know that in case of any emergency she can pick up the phone and call and after analysing our situation with my husband we decided together that I have to work again.*
>
> *The problem is that I have spent ten months looking for work and I cannot find a job. What happens is that with my mother-in-law I cannot work all day, I need to be back at home at 16h maximum in the afternoon and hopefully always have a fixed schedule so I can schedule the home tasks for my mother-in-law's care. But no one has accepted that, and I still haven't found a job. Now I don't know where to keep looking. (Victoria)*

Lucy, a 45-years-old, low-middle income woman, lives with her elderly dependent parents and her 19-year-old son. Two years ago, she needed a salary to pay for her parents' health and social care costs, and to maintain her house. Because of the difficulty of finding a job in Santiago she left town to work as a music schoolteacher in Antofagasta. Lucy was born in Antofagasta and a relative connected her to this opportunity. Antofagasta is 1,380 kilometres north of Santiago, and traveling from one city to the other is expensive. Her son who studied cared for Lucy's parents and did the housework with some help from Lucy's sister.

Four months later, Lucy had to quit her job in Antofagasta because her son was unable to provide care to his grandparents, do the housework and study at the same time. In addition, Lucy's sister did not fulfil the promise to help out. Lucy came back to Santiago and after desperately looking for a new job, she finally found one at a school close to her house. Usually while teaching, her father with Alzheimer's disease went to the school to visit her to tell her that her mother needed urgent help. It was generally not the case, and she was constantly and needlessly interrupted. While at work she was worried something could happen to her family. Lucy was laid off two months ago. She is convinced that she was let go because the school administrators were tired of her father's interruptions. She is desperately looking for another job. This job has to be close to her house because she needs to go to see her parents during lunchtime, to give them lunch, their medicines and make sure they are fine. So far, she hasn't been successful. This would allow her to have paid work and provide care and prevent financial constraints.

6.1.2 Care for an elderly family member is unpaid work

Another reason why caregiving for an elderly relative is a reason of experiencing economic constraints is that women's informal caregiving work goes largely unnoticed. It is consistently undervalued or devalued in terms of material rewards (Zembylas et al 2014). Caregiving is generally not considered as an activity that deserves a monetary compensation. For the great majority of carers in Chile, their work receives no monetary compensation (SENAMA 2009b). This adds to their economic struggle with medical and care costs and the difficulties they face in combining a paid job with their caring work. When carried out by a family member, care is not paid because it is not considered work. If carried out by an external person, it must be paid. Family carers are trapped in a job with enormous physical and emotional tension but without any monetary compensation, and few possibilities to access a job that would allow them to have their own income (Comunidad Mujer 2014).

Not considering family care as work has the immediate consequence of lost income and the long-term implication of making it harder for carers who spent years caring to re-enter the labour market. Several years out of paid employment brings scarring effects, as the labour market does not value interrupted careers. Also, as described in the previous section, carers become discouraged and lack self-confidence to re-enter the labour market.

Among the study participants, none of them received money for being their elderly parents or parent-in-laws' carers. The only exception were the few cases in which the elderly was enrolled in the Home Care Programme. Under this programme, developed by the Health Ministry and administrated by municipalities, the main family carer receives no more than 25 euros a month as compensation for their care.

Lucía, for example, a woman from a low-middle income household, the main carer of her elderly father and a single mother of three children, runs with the financial expenses of her father's care all by herself. None of her eight siblings cooperate. Lucía said that in an ideal world, she would like to receive a monetary compensation from the government for the work she does as a carer, that way she would not suffer the big economic constraints she faces every month.

Ana María, a high-income main carer, mentioned that her income security was a relief. She was also happy with externalising part of her mother's care. Ana María compared her situation with one of a friend without financial means to pay for her elderly mother's care.

> *My mom's care is very expensive. We pay, and that I find it cheap, a million and a half pesos [around 2,150 euros per month], without counting medicines, which are very expensive. We pay everything with the money that comes from my parents' fruit orchards today administered by my brothers. Luckily we can afford it and is not an issue for us. But I have a friend who does not have money, the husband is unemployed and has a big debt with the bank and she is younger than me, should have 58 years old, they are in a very good age to live alone together and enjoy life, but they can't because of the debts mostly coming from her elderly mother's care needs. (Ana María)*

However, besides the good economic situation of Ana María, she considers that the work she does being her mother's main carer should be compensated as any other job. Ana María's economic condition allows her to externalise all personal care tasks that her mother needs. Still, she recognises that the work she does managing and organising her mother's care should be paid by the rest of her siblings. She is using her time; she has postponed many of her personal activities and spends money on her weekly psychological treatment she receives since becoming her mother's carer. For her, her mother's care is a shared responsibility, not exclusively her own. Ana María met with her brothers and her husband a week before this study's interview to discuss issues related to the family agricultural business. Ana María's husband took the opportunity to tell Ana María's brothers that she deserved a salary for their mother's care work. Ana María felt embarrassed while her husband brought up the issue. They did not react favourably; they found it ridiculous. The issue was not discussed again and Ana María regrets having talked about it.

6.1.3 Elderly pensions do not cover the expenses of care

Another reason why main carers experience financial constraints is the low level of pensions elderlies receive.

> *What can one do with the 85,000 pesos per month [120 euros, the elderly pension that her parents-in-law receive]?*[71] *(Paz).*

In Chile, and as described in Chapter 4, elderly pensions are low (OECD 2015b). Being elderly is generally synonymous with being poor. The pension system is segregated between those that participate in the private pension insurance scheme and those that participate in the public scheme. High-income households generally participate in the private pension scheme. Low- and medium-income households participate in the public scheme. The private pension fund is a private insurance scheme, so pensions are proportional to the individual savings and may run out during retirement. Public pensions are generally lower and only minimal to cover basic needs. The average retirement pension in Chile for those in the private system is 182,000 pesos (260 euros), with less than 20% of the elderly reporting that they can meet their needs comfortably with their pension (Fundación Sol 2013). As of 2008, all elderly are eligible to a *Pensión Básica Solidaria* (Basic Solidarity Pension) amounting to 85,000 pesos (120 euros) a month which was increased, in 2016, to 95,543 pesos (135 euros). The average pension received by elderly in both the public and private system can barely cover a dependent elderly's care and daily living costs. The low income brought by the elderly impoverishes the carers' household and makes it difficult to externalise part of the caring tasks.

Not only are pensions relatively low, but health and medical care costs are high, with Chile having one of the highest levels of out-of-pocket health expenditure among OECD countries (OECD 2015a).[72] Pensions do not fully pay for health care not covered by the public health system. In the event of the elder requiring emergency care, family carers sometimes avoid the emergency unit of the public system and decide to pay for private health care to ensure care quality. In these cases, carers and their families engage in significant financial debt.

> *We are more relieved now. The first three years were difficult because she (my mother) received a pension, a pension of 113 thousand pesos (160 euros) but 100 thousand pesos were used to pay for her hip surgery. She fell down and we took her to the public hospital, but they did not want to give her a surgery, the public system did not want to spend its resources on an 84-year-old person, as was my mother when she fell and broke her hip. We took her to the hospital and after two hours they sent us to another hospital where she waited for two hours. They only measured her blood pressure, her vital signs and then they left her alone for two more hours. I was sitting at her side, then*

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[71] In 2016 the Basic Solidarity Pension was increased from 85,000 pesos to 95,543 pesos.

[72] Despite the last decade's advances towards a more generous and universal health care system, the Chilean population still draws heavily on out-of-pocket expenditure to get the needed and desired health care.

> *her eyes turned opaque and she began to decompensate, she went into the resuscitation unit, and until the next day we could not see her. Then we took her out of the hospital and took her to a private clinic where they did the appropriate surgery on her broken hip. It took us three years to pay the cost of that surgery. (Eugenia)*
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> *Medicines are also expensive in Chile and only a few of them are covered by the public health system. My mother receives a lower-than-average pension and medicines take up more than 75% of her pension. She gets 130 thousand pesos per month (185 euros), her medicines costs 100 thousand pesos each month, then she has 30 thousand left over (43 euros per month). Do you think you can pay for a living with 30 thousand pesos a month? (Carmen)*

Carers are forced to find supplementary sources of income to compensate for the elderly's low pensions. These include their own pensions in the case of retired or widowed carers (such is the case of seven carers in the study), paid job earnings (six carers), income from other members of the household (15 carers), contribution from siblings (eight carers) or a combination of these sources (four cases). From the study's 42 carers, only three were priviledged enough to have the elderly pensions high enough to pay for the elderly care expenses (these three cases are all from high-income households, but do not represent all high-income households in the study).

> *We live with her pension (my mother's) and mine. I started getting my pension one year ago, when I turned 60 years old. It is a very low one, because by being in the house taking care of my mom I was not able to save money for my pension. Before that, I worked as independent worker, and I managed to contribute to my pension for 10 years, but with ten years there is not enough for a decent pension, and therefore I get the minimum pension. Then all that makes me very sad, because I don't know how we will continue, because with both pensions, hers and mine, I don't have enough, and I manage to live using different credit cards, cards from the pharmacies, from Falabella (a department store), and then it comes the time of payment, then I get in debt again, and so on, as a circle that never ends. (Antonia)*

Some of the elderlies affiliated to the private pension system stopped receiving pensions because their funds were finished. Most of the private pension fund affiliates come from high-income households and have the benefit of a stronger financial support from relatives. Marita's 103-year-old mother stopped receiving a pension. Fortunately, Marita's five siblings have a good financial situation and collectively afford their elderly mother's care costs. They also have a good relationship so it has never been a problem to agree with money issues related to their mother's care.

6.2 When carers are elderlies themselves

Another carer characteristic that could become a constraint, or not, in their everyday life is when carers are older people themselves. As people live longer, the age when care is needed has shifted upwards. Men and women are less likely to need care in their 60s but more likely to be giving care to grandchildren and elderly parents (Wilson 2000). Today, there are more young elderlies taking care of their elderly parents than before. In this situation, carers do not have the same physical energy for caring for an elderly parent. Blanca is 78 years old. She lives alone with her 102-year-old mother with severe dependency and has been her main carer for 25 years since the onset of her mother's dependency. For the last three years, her mother has been severely dependent. Blanca provides most of the care: she prepares food and feeds her mother, she washes her in her bed and changes her diapers, she dresses her, arranges appointments with doctors and health practitioners, etc. Once a week, Blanca's daughter comes to help her to change her mother's bed linens.

> *A normal day is extremely exhausting for me. My feet are asleep at night and my back really hurts. I no longer have the same energy as I did before because I am old myself... being my mom's carer makes me very sick, but it's a moral obligation… (Blanca)*

Trinidad, who is 62 years old, also mentions how tired she is physically because of the force she has to do when caring her mom. Rodrigo, 70 years old, has to do daily exercises every morning to cope with the back pain he associates to the forces he does for her mother's care. From the cases of the study, all those who were older than 65 and from low and middle-income households and did not externalise any part of care mention that caring tasks impact their bodies negatively. Back pain is especially prevalent for carers in this age group.

For some elderly carers, however, their old age has helped them accept their role as carers. As will be discussed in more detail in a following section, the decrease in physical energy is not the only consequence of being an elderly carer as other difficulties or assets could emerge from this characteristic. Violeta is 62 years old, and retired a few years ago after working her whole adult life. She was looking forward to the possibility of free time and travel during her retirement. For her, her age is a constraint of her carer role, because it symbolizes that in caring her mom she is losing energy and time that she wanted to spend leisure activities or traveling. On the contrary, Josefina, who is also 65, is happy being retired and having raised all her children to be able to dedicate herself fully to her elderly parent's care. Marita, aged 79, experiences a similar situation. She raised her daughter and had her grandchildren living with her while they attended University. Now Marita is happy to have time to be dedicated to her mother's needs. As discussed in Chapter 7, the emotional component and the relationships are determining factors on whether age – or any other situation – become assets or constraints. While Josefina and Marita have a very good recollection of their childhood and their parents, Violeta still struggles with the past relationship she had with her mother. At their advanced age, their past explains their feeling towards their carers' role.

The caregiver's age by itself does not predict whether the care experience will be experienced as intense or not. Being a caregiver with an advanced age could be an asset, as is the case for Marita and Josefina, but it could also be a constraint, as is the case of Violeta. We need to investigate deeper to understand how the age of a caregiver could affect their experience and ultimately get closer to the factors associated with the intensity of the care experience.

6.3 Multiple caring demands

For many carers, care for elderly parents or parents-in-law coincides with other caring obligations. For the cases interviewed for this study, multiple caring demands involved caring of other family members (e.g. grandchildren, children, and/or partner) in addition to the elderly parent or parent-in-law. Women with multiple care responsibilities have been referred to as the *sandwich generation*, the *pivot generation* or *women in the middle*. These middle-aged women are caught between caring for elderly members of the family and caring for the younger members of their family (their own children or grandchildren) (Field et al 2013). It is common for women of this generation to be caring for some relative for the large majority of their life. On average, a women will spend 17 years of her life caring for her kids and 18 caring for their parents, with overlap in some cases. These estimates do not include the years women spend caring for their grandchildren if that's the case (Guzmán et al 2003). Whether or not they work outside their home, the dilemma for these women lies in trying to fulfil these multiple caring roles in addition to her roles as independent women, friends and/or workers (Brody 2004).

For Ana María, having multiple care roles is a constraint. Coming from a high-income family, having multiple care responsibilities means she doesn't have free time to keep a social life like she did before.

> *I don't hang out with my friends because I don't have time, and I even impose it to myself! I always have the list of friends I have to call or visit, for example a friend that has just had a surgery. But I can't visit her at the hospital because I don't have the time. (Ana María)*

The multiple caregiving responsibilities that middle age women have limit their possibilities to extend their social network outside the family, with important consequences for low-income families in light of the importance of social networks to offer support (Montes de Oca 2002). Lucy, a 45-year-old middle-low-income woman is a mother and main carer of her parents. She would like to have time to maintain her friends:

> *I don't have friends, the ones I had were school friends but now I don't see them. I like to be at home, whenever I have free time the only thing I want is to rest at home…*
>
> *…I don't have friends, I mean, it's not that I am closed to social relations, I talk with the neighbours and [to other people] in the meetings at my daughter's school, but I don't have those kind of friends that you can invite over to your place to have a cup of tea. (Lucy)*

Yet, some carers of elderly parents, show higher ability to cope with the weight of having multiple roles when they also care for children. It is possible that caring for children reduces this strain because children may help out with elderly care, provide emotional support to their parents, or provide the carer with another role (that of parent or grandparent). Adopting another caregiving role, and receiving the associated rewards, can offset the frustrations and difficulties associated with the role of elderly carer. Following the idea of *role expansion*, people can benefit from adopting multiple roles when the rewards from one set of responsibilities (i.e. raising a child, watching them learn) partially offset the frustrations and tensions of performing a second role (i.e. watching parent lose functioning) (Duxury et al 2009).

Indeed, for some carers in the study, multiple caring roles are a resource or asset; multiple caring roles is not necessarily a constraint. All carers in the study with multiple care roles find it difficult to manage all the tasks and feel exhausted, but some cases value having other people to care rather than only caring for their elderly parent.

We will now review how carers experience a) caring for an elderly parent or parent-in-law and grandchildren at the same time, and b) caring for their own children and the elderly parent or parent-in-law at the same time.

6.3.1 Providing care to an elderly parent and grandchildren at the same time

By the time their parents are getting older and need care, most adults are in the age of having grandchildren. In Chile, although the public provision of childcare is by far more developed than elderly care (Battany 2015),[73] a large share of childcare is provided by grandparents, who in some cases, care for their elderly parents as well (Zegers 2012).

Female carers of elderly parents in the study who also took on the role of caring for their grandchildren did so to ensure that their daughters could work. These interviewees with a double parent-grandchildren caregiving role are all middle age women and the children they cared for were their daughter's (not their son's) children. It seems as if maternal grandmothers are the first in line to assume grandchildren's care. Attias-Donut, Lapierre and Segalen (2002) also noticed this phenomenon and refer to it as part of a process towards greater gender equality, a change in girls' education and a new mother/daughter complicity in the fight to validate themselves in the public sphere, outside the family.

For Ana María, this fight is clear. Ana María is 62 years old and is the main carer of her elderly mother who lives in an expensive nursing home. Ana María is the only one among her four siblings living in Santiago and is in charge of all the organisation and management tasks for her

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[73] The Chilean government has made considerable efforts to expand childcare services. Since 2005, the number of free public nursery places for children aged 3 months to 2 years who are living in the poorest areas of the country increased from 14,400 to 64,000 in 2008; in addition, pre-primary places for children aged 2-4 years, which numbered 84,000 in 2005, were expanded to about 127,000 in 2009. The current government has announced the creation of 90,000 places for early childhood care, bringing enrolment of infants aged 0-2 to the OECD average.

mother's care. Among her siblings, she is the only one engaged in her mother's care and feels exhausted. She also has four daughters, one son and twelve grandchildren. She has been a housewife since she got married. After finishing school, she studied landscape design and has had sporadic jobs as a garden designer, but her priority has been to raise her children. When Ana María refers to her husband, she highlights he is an intelligent man with a successful career, but that his role is only that of a breadwinner. She carried with the responsibility of caring for the dependent members of the family, postponing her professional career. She finds that this arrangement is not fair and would not like to see the pattern repeated in her daughters' lives. For her, it is a priority that her daughters work and progress in their professional careers. Anytime one of her daughters has a problem with their children's care arrangements, Ana María is there to help.

> *I tell my girls, do not ever stop working, I would always help them as much as I can with childcare so they can continue working, even if that's a huge work for me because I am most of the time involved with my mom's stuff. (Ana María)*

The childcare support women caring for their elderly parents give to their daughters so they can go to work was observed across different income levels. Andrea, 40 years old from a middle-income household, is the main carer of her mother-in-law and her aunt-in-law, both elderlies with cognitive dependency and physical dependency. She is also the main carer of her six-month-old granddaughter. They all live together, with Andrea's husband, her two daughters and her granddaughter. The two elderlies and the baby are completely under Andrea and her husband's care (he works from home as a stained glass artisan and actively participates in the caring tasks).

Not long ago and after caring for her mother-in-law and aunt-in-law for eight years, Andrea managed to find time for herself. She was able to see her friends occasionally and to finish secondary school by enrolling in night programme; she planned to continue on to post-secondary studies. However and shortly thereafter, her 16-year-old daughter got pregnant. Andrea and her husband were sad and felt guilty thinking that they had put their daughters aside by being too engaged with elderly care. Moved by these feelings, Andrea decided to become her granddaughter's main carer so that her daughter could continue school, finish her studies and go to University. Andrea gave up the little free time she had and her own dream of going to University. Giving her daughter the opportunity to go to University and having a well-paid job compensates for her own postponement and tiredness.

Grandmothers are involved in their grandchildren's care in different ways. When grandchildren are in school age, grandmothers are carers during school vacations and/or afternoons. They also adopt a caregiving role if children become sick and parents can't be absent from work. Often, if grandchildren are younger than five, the age at which primary school enrolment becomes mandatory, grandparents are their carers for the whole day while their parents are at work.

Caring for grandchildren while caring for elderly parents is sometimes a positive experience but it can also be a negative experience, or even a responsibility grandparents prefer not to take (these cases are less frequent).

Trinidad is the main carer of two of her grandchildren during summer vacations. While she provides care for them she provides care for her 98-year-old mother with severe dependency and her 68-year-old brother with an advanced functional disability. For her, caring for her grandchildren is something that she enjoys plenty, and gives her energy for the rest of her daily responsibilities. She exemplifies Duxbury et al's (2009) idea of role expansion. For Trinidad, the rewards from childcare offset the pressures of elderly care. She enjoys helping in her grandchildren's development and watching them learn and grow. When she talks about her mother's and brother's care she shows tiredness and frustration; when she talks about her grandchildren's care her eyes shine and a slight smile appears on her face.

> *I like being with my grandchildren here, they are seven and eight years old and they are good children. We spend all summer vacations together at my mom's place. Of course it is sacrificed for them because they accompany me while I care for my mom and my brother. But I like to be with them, I teach them good things, I teach them values, the importance of being honest and helping other people. (Trinidad)*

For Trinidad, her multiple caring responsibilities are not constraint. While being her elderly mother's carer is a source of pressure, being her grandchildren's is a source of pleasure.

The same cannot be said for Carmen, who provides care to her grandchildren during the week while also caring for her elderly mother. She accepted to care for her grandchildren because she needed to earn some money (her daughter pays her for taking care of the children) and wants to support her daughter's professional career. Carmen recognises, however, to be very tired at the end of the day and that the ideal situation for her would be to enjoy the presence of her grandchildren once in a while but not being their main carer on a daily basis.

Though usually it is expected by daughters that their mothers are available to help them with their own children's care, not all grandmother-carers of elderly parents agree to take responsibilities for their grandchildren's care. Isabel, a 51-year-old carer for her severely dependent father and her low-dependent mother, refused to take care of her granddaughter. Her daughter and granddaughter live with her, but Isabel won't budge even if her daughter is very angry with her.

> *I live with a daughter and a granddaughter, but it is my home and I'm the one in charge of my house and do my thing as I like. They tell me I'm never at home and my daughter complains at me for not helping her with Belén, my granddaughter. But I said no, I tell*

> *her that I already raised her, I already was a mother. My daughter is 27 years old and my granddaughter is seven. I say that her mother is responsible for her and that I am her grandmother, but she does not accept that. My daughter gets angry. I am over 50 years old, I have my own home and I do not need anyone giving me orders, I'm very strict in that regard. I'm not like all grandmothers now that take care of their elderly parents and their grandchildren. I've done my work raising and now I'm in another stage, besides taking care of my parents I want to live and take advantage of the little free time I have left to enjoy my remaining years with good health. (Isabel)*

Josefina has three sons, a daughter and six grandchildren, who she doesn't see very often as she cares for her own dependent parents. Her daughter is not happy with the fact that her mother is not available to help her with childcare. Josefina doesn't want to change the situation for the moment.

> *I have postponed my grandchildren, especially my daughter's girls, it took her five years to have children and then she had four babies in five years. The compatibility of tasks is difficult. Being a grandmother in Santiago is not easy with the traffic jams, school schedules that finish late and if you want to see them after school then it takes at least an hour to come back home. Now they [the grandchildren] are well aware that I'm caring for my parents and they respect that, they are aware that their grandmother has her own very old parents to take care of. But my daughter gets angry sometimes, I noticed that, for example, when she was having her fourth baby and I could not help her much, she really made a huge effort to put up with it. Sons ask for nothing (laughs), they are wonderful, women are more demanding. (Josefina)*

6.3.2 Caring for own children and an elderly parent at the same time

Carers of elderly parents who have children under the age of 18 probably have another dependent family member under their care themselves. Not all carers experience this double care demand, this double role, in the same way. For some cases, caring for their own children and an elderly parent or parent-in-law is a tiring experience. For other carers, caring for the elderly is not a major constraint as it is seen as one more dependent family member to care for. The latter is the case for Fátima. She lives with her three children (all less than 18 years of age), her husband and her dependent mother. She describes her life as a series of never-ending caregiving tasks. She wakes up at 6h every day. From then on, she barely stops caregiving. First, she gives breakfast to her children and prepares their school lunchboxes. When her children are at school she cares for her mother; Fátima is in charge of all caregiving duties. When her children are back from school she has to combine the attention between her mother and her children. In her words, "*I never end*." She also referred to the fact that as her children are older, she is almost done with their caring responsibilities, but as her mother ages, she requires more intensive care. Fátima postponed her professional career while raising and caring for her children; although she would like to look for a job, being her mother's carer hinders her desire to seek employment.

By contrast, caring for her children and her parents simultaneously is not a big issue for Elisa. She lives with her seven children (all under the age of 15), her husband and her dependent mother-in-law. She experiences being her mother-in-law's main carer as just one more responsibility and task in her daily agenda. Elisa's caregiving role is mostly managerial. She externalises her mother-in-law's direct and personal care from 9h to 18h (a woman comes to assist her mother-in-law with her personal care including bathing, dressing and cooking). Organising her mother-in-law's appointments with doctors and coordinating the help she receives from a paid carer is not a source of pressure.

> *It is not that being her carer does not change my daily life, I have to change my schedules a little bit, and, above all, the biggest change is being always attentive to her needs, but every medical appointment or special event related to her, is just one more appointment in my agenda, and I have seven children so, honestly, having my mother-in-law under my responsibility doesn't feel very different. (Elisa)*

For carers who are exclusively dedicated to the elderly care and have already provided care to their now independent children, the experience can be difficult. While caring for their children, they had looked forward to a period when they would be free of caring demands. Then they feel overwhelmed when parental care begins to dominate their lives (Abel 1991). This is Violeta's case. She is now retired, and her only son lives independently. During her working life she dreamt about the moment when she would retire and be relieved from the need to balance work and caring for her son. She dreamt about having free time to spend on her own interests. She is frustrated, however, for having to spend her time as a retired worker taking care of her mother. She had saved money for traveling, but used that money to remodel her house instead as traveling is not an option while caring for her mother.

The intensity of the caring experience for those who have multiple care demands is not determined by the amount of hours spent per day providing care or by how many family members they have under their care. In some cases, the more members under their responsibility provide more sources of satisfaction. In other cases, multiple caring demands is synonymous of a greater intensity of the care experience. It is necessary then, to continue delving into the phenomenon to know the factors associated with the intensity of the care experience.

6.4 Balancing a paid activity with care work

Having a paid job in addition to caregiving for the elderly parent or parent-in-law is another situation that can add (or not) constraints to carers' lives. Having a paid activity may appear to be an additional difficulty for the carer of a dependent elderly, but the reality is more complex (Campéon et al 2013). Having a paid job while working as a carer could be a source of satisfaction and personal fulfilment (Baudelot and Gollac 2006). The paid activity can be experienced as respite from caregiving demands and become a resource for coping with care responsibilities. It can also be a source of protection against an extreme level of investment in caring responsibilities (Le Bihan and Martin 2006, Le Bihan, Martin and Knijn 2013).

Working conditions, family and care policies, and culturally-defined patterns of intergenerational and gender relations determine the context in which male and female family members are able to cope with work and care demands for elderly in need of care (Knijn, Martin and Le Bihan 2013). As in Chile there are no elderly care conciliation policies for people engaging in paid activities, the job characteristics, the social support and the cultural patterns of gender relations may contribute to how carers experience the balancing of care work and paid activity.

Carers are more likely to work part-time or not at all (Colombo et al 2011) and those that do retain their jobs often have to make major changes to their work schedules (Alzheimer's Association 2013), miss work more often than their peers (Tilly 2007) and earn less than non-carers (Knapp et al 2007). This has a general economic cost to countries if carers would otherwise be in higher productivity jobs and the reductions in tax revenue from people exiting the formal workforce may partially offset savings to government budgets from reduced spending on formal care. In addition, since most working-age carers are women, a greater role for informal care has a negative effect on gender equality in the labour force (OECD 2015b).

As in other familialistic welfare regimes, in Chile as already discussed, the main responsibility for welfare corresponds to families and women in kinship networks. Given this reality, the ability to remain in the labour market and balance paid work with caring for an elderly family member differs between men and women. It also differs across social class, as a function of the availability of private resources to externalise care (Saraceno 2010).

Women develop different strategies to reconcile paid work and caregiving in familialistic regimes. Three strategies are identified: *reducing goals* at both the level of paid work and care work; *delegating* or transferring all or part of care or paid work to another person; and thirdly, the *sequentialising,* or alternating production for the family and for the market (e.g. taking maternity leave or leaves of absence from work to provide care) (Durán 1999). Of the 15 carers in this study who combine paid work and caregiving, most adopt a *reducing goals* or *delegating* strategy.[74] The strategy adopted by the study's caregivers differs according to their socioeconomic status. High-income carers tend to delegate, low and middle income tend to reduce their goals to balance unpaid care work and paid work.

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[74] In Chile, few family carers combine paid work with care (11%) (Comunidad Mujer 2012). This pattern is reflected in this study's cases, as 15 of the 42 cases had a paid activity in addition to caregiving and from in the difficulty of finding paid work that allows it to combine with care duties.

As with other potential constraints, the pressure felt when balancing paid work and caregiving for an elderly parent or parent-in-law cannot only be explained by the accumulation of constraints or their combination, nor solely by the strategy adopted to be able to combine both activities. Objective and subjective variables need to be taken into account to understand why and how balancing paid work with care become a feeling of pressure (Campéon and Le Bihan 2013). These variables include the availability of social and financial support, the characteristics of the job and the carers' meaning for the job. Furthermore, for a deeper understanding of the care experience, the emotional and relational aspects need to be taken into account, both of which are developed in Chapter 7.

This section explores the lives of caregivers who combine their carer role with paid employment and reviews the factors that make the balancing of both roles easier or more difficult. These factors include: a) the social and financial support, b) the characteristics of the paid job (e.g. job demands and control, flexibility and employer support), and c) the primary meaning given to the job (e.g. job as a respite, as personal and professional fulfilment or primarily as a source of income).

6.4.1 Social and financial support make the balancing easier

A turning point arises when individuals are faced with having to provide elderly care and maintaining paid work. It affects their career paths dramatically and in potentially irreparable ways. Social support and financial means become crucial in determining the direction of this turning point; that is, in balancing paid work with elderly care. Social support and financial allow carers to adopt a *delegating* strategy and carry out caring duties and have paid employment at the same time. Formal and informal supports can allow carers to keep their paid jobs and the elderly care in separate spheres, irrespective of the physical and mental health of the elderly (BID and Comunidad Mujer 2014).

In Chile, however, and as described in Chapter 3, less than 10% of the elderly in need of care are under the care of a person or entity (nursing homes) through paid or unpaid services (SENAMA 2009b). Only a small share of households can externalise care through paid arrangements and charitable organisations serving low-income elderlies have long waiting lists. In general, for the rest of the population, there is practically no institutional support for elderly in need of care (Comunidad Mujer 2014). The lack of social and financial resources and the scarcity of formal care offers make the balancing of a paid job and elderly care a source of tension. It also means that labour trajectories get interrupted or changed.

Among the interviewees, those without the financial means to externalise caring duties and who maintained their paid employment reduced their working hours to be able to combine their jobs with their carers' roles (*reduction of goals* strategy). Despite the reduction, some cases felt that both roles could not be fulfilled successfully with ease. Bernardita, Claudia, Paz and Lucía,[75] all four women from low or low-middle income families, all of them working informally (three as cleaning ladies and one as a street singer), leave their elderly parents alone for a couple of hours a day. Leaving their elderly parent alone is a source of worry for them. In addition, the reduced working hours means a reduction in their salaries. For women in low-income households this becomes a serious constraint, increasing their chances to fall and remain in poverty. Lucía, for example, reduced her working hours as a full-time informal cleaning lady. Even though she has eight siblings, none of them participate in the care arrangement. She is all alone caring for her elderly father and her 10-year-old daughter.

> *I work, but I used to work more in the past. I work in private homes as a cleaner, to be able to maintain my daughter who is ten years old and my dad. But since I care for him I left most of my work and they were good jobs that paid well, I had to leave them to take care of him. (Lucía)*

Monetary resources could allow for balancing paid employment and care without generating a feeling of pressure. This is especially the case in Chile where the public support for elderly care is precarious.

In this study, high- and middle-income carers who decided to continue with paid employment while taking on the role of main carers adopted a *delegation* strategy. They are able to hire someone external to the family to contribute with caregiving tasks. Adela, a full-time secretary, Pedro a full-time office assistant, Consuelo, a part-time secretary, Penélope, a school psychologist, and Aurora, an independent accountant, were all able to combine their paid work with caregiving. They could do so because their salaries were sufficient to pay someone else to help with caregiving tasks.

Being able to maintain a paid job because it is possible to externalise part of the caring duties does not necessarily bring about a smooth balance between care work and employment. Selection of the external carer is not an easy task; many carers are reluctant to leave their parents under the care of a stranger. For many carers it takes time to find the right person. They have to supervise and manage the external carer, which also poses difficulties for family carers.

In addition to having the means to externalise care, other factor influence how carers' experience balancing the double role of paid workers and carers. These factors include flexibility in work arrangements, the meaning associated to one's job and the social support carers have inside their household and families.

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[75] Carers having flexible jobs that allow them to combine paid work and care are usually engaged in precarious jobs. These are informal jobs without contracts and no social or labour protection and offering low salaries.

Despite the lack of monetary resources to externalise care, Paula juggles complicated care arrangements to be able to work, even considering that the financial returns to her job as a part time saleswoman are limited. Every morning she gives breakfast to her 92-year-old mother with whom she lives. Her sisters take turns to care for their mother while Paula is at work (she has four sisters and two brothers, five of her siblings live on her same street). Paula was one of the few cases in which the interviewee mentioned that all sisters were very involved with their parent's care. While Paula is at work, she knows her mother is under good care and that she can receive other forms of support from her sisters who also help with the household chores (e.g. cleaning her mother's bedroom and washing her clothes). For Paula, being her mother's main carer and being employed does not impose pressure in her life. The social support by the part of her sisters and her flexible working arrangement does not create a feeling of pressure.

Social support from family members is also important for carers who externalise care while they are in paid work. Coming back home to assume the role of carer after a full or part time day at work is easier when there are other hands available to help with household tasks and also with caring tasks. Pedro works full time, five days a week as an office assistant. He lives with his elderly parents and his mother has severe dependency. While at work, Pedro has a paid carer looking after his parents. When he comes home, Pedro is fully dedicated to his parents, but receives support from his wife and, to a lesser extent, from his daughter. His two sisters take turns during the weekends. This allows Pedro to rest, regain energy and start Mondays capable of balancing his paid work and parents' care with no strong intensity.

Social support and concrete and tangible help is more likely to be offered to male carers who have a paid activity than women in the same situation. This is in line with the observation that, in Chile, though more women are going into the labour market, there is no evidence for a comparable increase in men's participation in caring tasks and domestic work. The rigid gender distribution of work inside Chilean households remains despite changes in employment and labour force participation (Arriagada 2011). In Chile, women who are in the labour market commonly have a *second shift*. The first shift consists on taking care of most of the household and caring responsibilities while the second consists on paid employment (Hochschild and Machung 2012). Such is Ofelia's case, which contrasts with Pedro's case outlined above. Ofelia works full time as a teacher in a school for deaf children. Ofelia lives with her husband and her youngest daughter. Her father, with moderate dependency, lives in the house next door. During the interviews she seemed tired and recognized it. She said she would like to stop working because she is tired of her double shifts, one at the school and one at home. She receives no help from any of her relatives or from her husband when it comes to her father's care or household chores. By contrast, Pedro receives strong support and concrete help from his two sisters and his wife. Pedro also received help from his neighbours and friends. No matter the socioeconomic status or age, male carers in this study received more help than women in similar situations. Balancing care work and employment is felt with less pressure for Pedro, than for Ofelia, as a result of the social support and concrete help received. The lack of support received by women caregivers in paid employment might be the result of the cultural belief that care is natural to women and that men engaged in care deserve support and help as care would not come naturally to men.

6.4.2 Job characteristics can facilitate balancing caregiving with a paid job

People with employments and care responsibilities have to consider how to achieve the right work-life balance. Their job's characteristics and sectors influence the options available for carers to reach a satisfying balance between paid work and care demands (Knijn, Martin and Le Bihan 2013). Job characteristics found in the study related to how carers experience elderly care are i) job demands and control, ii) job flexibility, and iii) employer support. These characteristics are reviewed in this section.

i) Job demands and control

One job characteristic that can (or not) be a source of pressure for workers is the combination of a high degree of *job demands* with a low degree of *job control*. This combination can have a negative impact on carers' life balance. Job demands refer to the pace and emotional and cognitive demands stemming from one's work. Whereas a moderate degree of demand provides stimulation, jobs that are too demanding may cause tension. A higher degree of job control, on the other hand, tends to reduce the pressures by giving workers some degree of autonomy over how to carry out the work tasks. It gives workers more autonomy over the balancing process, in many cases, positively affecting individuals' ability to reach a satisfactory work-life balance (Fagan and Walthery 2011).

Penélope has a combination of job demands and job control that allows her to reduce the tension of balancing her parents' care with her paid activity. She is both of her parents' main carer. Her parents live a two-hour drives away from her (Penélope lives in Santiago). Whenever there is an emergency she has to be there for her parents. She sets their medical appointments and takes them to the hospital and medical exams. She also works, Monday to Friday from 9h to 18h as a school psychologist in a school attended by children from disadvantaged social backgrounds. Her job consists on individual therapy sessions with students, meetings with school's teachers and meetings with the children's parents. She recognizes she is often tired, but she is at the same time happy with the possibility of combining her parents' care and her paid activity. Helping vulnerable children and families in her job gives her a sense of fulfilment. She also appreciates the fact that she is able to manage her work schedule; she is able to decide when to have meetings with students and their families, referring to another job characteristic that facilitates the employment and care balance, flexibility.

ii) Flexibility

Perceived flexibility in the timing and location of paid work is related to positive outcomes from personal, family and business perspectives. Higher perceived job flexibility enables employees to have a satisfactory work-family balance. It also allows employees to work longer hours before work begins to impact work-family balance. Job flexibility refers to flexibility in working time (*flexitime*) and flexibility in the place of work (*flexplace*), giving workers varying degrees of control over when and where they fulfil their work commitments. Both flextime and flexplace reduce the burden associated with the daily commute. The ability to leave the workplace, work from home and arrange working hours alleviates the logistical difficulty of arranging for elderly daily care (Hill et al 2001).

Florencia balances her job and caring duties without any feeling of pressure. She benefits from both high levels of flextime and flexplace. She digitises survey data for a company that conducts surveys. Her mother, with Alzheimer's disease, attended a nursing home for a time but when costs were too high, Florencia decided to quit her job and care for her mother full time at her house. Two years after quitting her job and remaining out of the labour force, she has returned to working for the same company. They offered her the possibility of working from home with the ability to choose her working hours. Florencia can now have a salary and a continuous work experience while caring for her mother. Although it is not a large salary, according to her it is better than nothing. Importantly, her digitiser work allows her to disconnect herself from her caring duties, offering a respite from caregiving.

Yet as with other context factors being constraints for some carers but not for others, flexibility can also contribute to carers' fatigue. Carers with flexitime spend many hours in caring duties and end up working for their employment until late hours at night. This is the case of Aurora, from a high-income household. She works from home as the family construction company's accountant. She is the main carer of her elderly mother who has moderate-to-severe dependency. Her mother lives a 25-minute drive away from her with a nurse and domestic service. Aurora visits her mother daily as she is in charge of her mother's care and the administration of her mother's house. She wakes up early every morning to get some accounting work done. She then visits her mother, returning to her house in the afternoon or evening to have dinner and continue her accounting work until late at night. Although her job's flexitime and flexplace allows her to combine employment and care, it does not flow smoothly. For Aurora, it adds difficulty and is a source of fatigue.

Flexibility is not always a synonymous with a paid-work-and-care balance that is not free of tension. It could rather well be a source of difficulty, particularly in the context of precarious employment. Bernardita, a low-middle-income woman who cares for her elderly father with moderate dependency, works as a cleaning lady for different people. As her father's dependency increased, she was able to keep part of her job by reducing her working hours. Although it is positive that she could keep part of her job, her monthly earnings declined by 60%. Dedicating herself to her father's care increased her financial constraint.

> *I now work fewer hours, because last year I worked every day, Monday to Friday, arriving late at home and leaving early in the mornings. Then, last year when my dad's health was more fragile, I began to work less, to take better care. Then I started working three days, and now I work only two. (Bernardita)*

An informal job like Bernardita's offers her the flexibility to reduce working hours depending on her father's care needs and at the same time continue working, but at the expense of much-needed earnings.

Sara is another example of how a flexible job has allowed her to combine her mother's care with a paid activity. Before, she worked as a paid carer for elderly people, but she quit because she needed to dedicate herself fully to her mother's need. She has decided to put in practice her pedicure knowledge gained through a course she took when she was young. She works from home as a pedicurist, allowing her to have paid work while still supervising her mother. This arrangement has allowed her to earn some money, be in contact with other persons and have something to think about beyond her mother's care and household issues.

Unfortunately, flexible jobs are often informal, precarious and unstable. These jobs are usually low paid generating both income and job insecurity.

iii) Employer support

The experience of balancing a paid job and care results in different experiences depending on the level of support received from employers and colleagues. In Chile, there is no law or formal arrangement that gives workers the right to be absent while caring for an elderly sick parent. There is generally no right to take unpaid leave, so balancing any emergency or unforeseen increase in care demands depends highly on the employer.

Francisca is the main carer of her moderately dependent 88-year-old mother. She works full time as an environmental engineer in the same agency as her husband. They have a daughter, and she has a brother who does not participate in their mother's caring arrangement. Two months before our interview, Francisca was absent from work while her mother was hospitalised for four weeks. Francisca discussed an informal arrangement with her employer that allowed her to be absent for that month and keep her job. The arrangement consisted on taking all her and all her husband's vacation days, which summed one month. She recognizes she has a nice boss, and is unsure she would have been able to accompany her mother if working for a different employer. If that were the case, she would have had quit her job in order to be able to care for her mother.

Pedro works full time under a legal contract as an office assistant. With his salary, his wife's earnings as a cleaner, and the monetary help from his two sisters' families, he can pay someone else to take care of his mother while he is at work, from 8h30 to 19h. He has never thought of quitting his job to care for his mother full time. He says his employer has been very supportive. He can take a day or a half-day off to take his mother to the doctor or to visit her at the hospital if that's the case. He feels his employer and colleagues are understanding of his situation as they show concern and are permissive and comprehensive with his absences. Interestingly, he recognises that they are supportive with him because he is a man. If one of his sisters were the main carer, he believes they wouldn't receive the same support from their employers.

> *I have all the support from my bosses, but I think if my sisters were taking care of my mom they would no longer be able to continue in their [paid] work. With women I think the situation is different, as it is more natural to take care of the parents and the children, then society is less understanding when they also work. It is as if they don't need as much support as men need to be able to work and care at the same time. (Pedro)*

6.4.3 The meaning of a job

The personal meaning carers give to their role as a worker in a paid activity is key when understanding how they experience the balance between care and paid work. For carers the job can be seen as i) a respite from caring duties, ii) a source of personal fulfilment, and/or iii) only as an income source.

i) Job as respite

Women like Catalina or Bernardita face some difficulties when balancing care and paid work. The combined roles are a constraint in terms of lower earnings, higher tension and fatigue. But despite the difficulties, combining paid work and care provides positive aspects for carers' life as well. Carers may, for example, find a paid job to be a means of gaining respite from their caring demands (Carmichael and Charles 1998).

Catalina is the main carer of her cognitively and physically dependent mother. She works as a secretary, Monday to Friday from 9h to 13h. While Catalina is at work, her sister, who recently moved in to live with them after a divorce, stays with her mother. Arriving home at 13h, Catalina is completely in charge of her mother's care and the household issues. For her, the most important aspect of having paid employment is the chance to get out of the house and be immersed in a different atmosphere. The source of respite offered is particularly evident when considering the difficult working conditions she faces:

> *I am sure that if I am not out working in the morning I would go crazy. Although my job is sort of crazy (laughs) [because] my boss screams at me all the time. But it is still a different situation to the one I have at home every day with my mother. I work because I need the money but mostly because I need something for me too. I am a secretary and my boss yells at me every day… and they pay me nothing, 240 thousand per month [345 euros], but I tell you, this is something mine and different from my mom's caring obligations. (Catalina)*

Bernardita is the main carer of her father with low dependency with whom she lives. She is 53 years old and comes from a low-middle income family, originally from the Chile's southern countryside. She has four siblings; her two sisters visit her and her father once a week, providing mostly emotional support to their father. Her brothers *"live their lives and are not close to the father."* Bernardita maintains the household with his father's pension (approximately 145 euros a month) and Bernardita' salary (100 euros). She used to work as cleaner for five days a week, but as her father's dependency increased she reduced her working hours to two days a week. For Bernardita, the most important part of having a paid job is receiving her money, so she is not pleased with having to work fewer hours. Yet, Bernardita also likes to have a paid job as it offers respite from her caring duties.

> *When I'm at home it's all day that I am preoccupied about him, even at night I'm preoccupied about him, if he is sleeping well, I could say that when I am at home I'm preoccupied about him 24 hours a day. When I work it's just when I arrive home. It's not that I forget him if I'm working, I call him to be present, but it's sort of a respite for me, even though my work itself [cleaning houses] is not something that I particularly like, but it's a disconnection, and plus, I have the luck of working for nice people. (Bernardita)*

ii) Job as professional and personal fulfilment

Colomba is 36 years old and is the main carer of her 84-year-old father who has a low level of dependency. She belongs to a high-income household and manages her father's medical appointments, takes him there and is in charge of the house they share. A woman comes three days a week to help her with household chores; her brother visits her father two or three times a week after his job to offer emotional support. For most of the time, her father stays alone while she works. He has no need to be accompanied at all times because he is autonomous for most basic daily activities. Colomba works as a landscape architect and loves her job. She doesn't have flexible hours or a flexible place for work. She has no problem balancing care and paid work because landscaping is what she always wanted to do. Being her father's main carer doesn't hinder her possibility to find fulfilment in her job. The example laid out by her mother is important. Colomba's mother loved her job as a University professor when she cared for her children; she enjoyed both roles of being a carer and a worker.

Paz, from a low-income household, is 54 years old and is the main carer of both of her moderately dependent parent-in-laws. She works mainly weekend nights with her partner as a mariachi (street singer). She has been singing for 30 years and, above all, loves her job. She also does it because they need the money. Although they would prefer not to leave the elderlies alone while they work, it's not a big source of worry because they enjoy singing and forget everything while they sing.

There are limits, however, to the extent that professional fulfilment reduces the pressure of any interference between the two roles. Other factors that put a limit on the extent to which fulfilment alleviates pressure include the elderly's level of need and the supports carers may have from other sources. Colomba enjoys the personal fulfilment landscaping offers her; yet her father has a low level of dependency and she receives the support of her brother and an external carer three times a week. By contrast, Lucy loves being a music teacher but her passion for it is not enough to have a work and care balance free of tensions. She is 45 years old and worked as a music teacher in a school near her house (she lost her job two months before the interview). She is the main carer of both her parents, her father with a cognitive dependency and her mother with a physical dependency. Her son who is 19 years old and helps her once in a while with caring duties, but most of the time she is all by herself. Her one sister does not participate in the care arrangement.

Although Lucy loves being a music teacher, combining the two roles was very challenging because of how care and what care means for her interfered with her job.

> *What worries me most in my life is that they are alone while I am working. In fact, when I'm at work I call them during breaks, every morning I leave the phone right next to my mother. 'Is everything OK?' 'Did my dad wake up?' 'Did you have breakfast?' That kind of control and questions, every day. Because for me it is a concern. In fact, I think most of the jobs I've lost have been more than anything because I have had to get out fast every time there was an event in my home with my parents... It is a constant stress. (Lucy)*

These cases illustrate how complex the experience of balancing care and paid work is. There is not only one factor determining how much difficulty a carer will experience when balancing different roles. For Lucy, Paz and Colomba, their jobs offer personal fulfilment, but paid employment and care is experienced in different ways. Indeed, the factors predicting the intensity of a care experience are many and interrelated. They include, as will be developed further in other sections, the relationships the carers have with the elderlies and their perceptions towards their carer role, among others.

iii) Job only as an income source

Caring for an elderly parent is very expensive and can have considerable financial implications as a result of everyday care costs and physical and mental health care costs (Bittman et al 2004). It is usually the family carer or her/his direct family that assumes these costs in countries like Chile where wages and pensions are low and there is little support for elderly care from the part of government. For carers, paid employment can have meaning in terms of the income it provides (Carmichael and Charles 1998). It was common among working carers in this study to hear that employment was a way to increase the household income. When supplementary income was the primary or only meaning for the paid job, it was harder for carers to be satisfied with their care work-paid job balance. For them, having a job was often experienced as a tense situation.

This is Lucía's case. She lives with her daughter and her elderly father. She works because she needs to maintain her household. She works as a cleaning lady for different families every day until 14h. She also irons and washes neighbours' clothes so she can earn extra money while working at home and remain attentive to her father needs. She works because she needs the money. The main and only meaning that Lucía sees to her paid activities is to earn money.

> *Look, I need to work to care for and feed my dad and my daughter. My dad's care gets expensive. For example, I have to give him vegetable soups, cooked fruit juices, things that I usually didn't have in my fridge before having him at home. (Lucía)*

During the interview, Lucía mentioned that if she ever met her municipality's mayor she would ask him to give a salary to carers of elderly parents so that they could stay at home rendering a good quality care. This would exempt carers from having to work to earn money. For Lucía having to balance a paid activity with her caring role implies a source of pressure, leading us to think that the meaning of a paid activity only as a source of income is not enough for a successful balance of and work life balance.

Cases where a paid job made sense to carers as a source of professional fulfilment or respite from caring duties didn't experience the double role of carer and paid worker as a worrying experience. In this study there was no case of a carer with a paid activity mentioning that he/she worked only because they enjoyed it or that they work mainly because they look for fulfilment through their job. For all cases in the study that had paid work, additional income was an important source of meaning for their double role.

One conclusion from the description of the different situations and constraints related to balancing a paid activity with caring work for an elderly parent or parent-in-law is that there is no single explanation or isolated factors determining how carers experience this balancing. Neither job characteristics, social and financial support nor the meaning attributed to the paid activity comprehensively explains how carers experience their double roles. Other roles and factors need to be considered; they include the elderlies' health characteristics, carers' other roles and their financial situation. Moreover, the meaning of their role as carers, the relationships and the family and own history determine carers' experience, in addition to the employment situation. The following sections will elucidate these other factors.

6.5 Elderly characteristics: The challenge of caring for a highly dependent elderly

An elderly person's characteristics, both personal and situational, are another factor that could become a constraint (or not) for carers' and define their experience (Brubaker 1990, Campéon et al 2013). Relevant elderly characteristics for carers' experience identified in this study include the elderly's level of dependency and the nature of their pathology. The elderly's financial situation is another relevant characteristic of the elderly that contributes to potential difficulties that carers face in their everyday life, but it has been discussed in the context of carers' economic constraints.

In general, the older elderly people are, the more vulnerable they are to disability. The older elderly people are, the heavier the care needed and the greater the constraints their care can pose on the carer's life (Brody 2006). An elderly's dependency level is related to the time and energy that a carer needs to devote to the provision of care. When elderlies cannot move and cannot cooperate with movements, or when they have changes in their personalities and unpredictable behaviours due to dementia, for example, their carers need to exert more physical force, require more psychological and emotional strength and need to devote more time for the elderly care. This increases the carers' risk of physical fatigue, tiredness and emotional sorrow.

The provision of care could be a source of tension for carers because of a lack of emotional preparedness to assume an elderly's new condition or because of their sense of efficacy when they think they do not have the knowledge to give proper care to a parent with high dependency. These sources of tension come in addition to the grief associated with the fact that a highly dependent elderly might die soon. Carers of an elderly parent with cognitive dependency due to dementia also experience the difficulties of accepting their parent's new personality, their behavioural changes and the new relationship with the elderly.

High levels of dependency are likely to be a constraint for those carers who receive no help. In Chile the majority of the carers of elderly people (53%) do not share the caring tasks with any other person (SENAMA 2009b). In this study, 12 of the 42 carers received some help from other people for their caring tasks. The other 30 cases provided all care by themselves irrespective of the elderly's dependency level.

The two biggest challenges for carers caring for a severely dependent elderly are i) accepting the severe dependency condition of the elderly and their lack of knowledge on how to provide care, and ii) having to deal with a new reality for cases with an elderly with dementia. The following sections review these challenges together with the way carers experience them.

i) Accepting the severe dependency of an elderly parent

The first months of assuming the role of carer for a parent or parent-in-law can be difficult when the elderly has a high dependency level and the carer feels unprepared to face the elderly's new condition. Carers have to adjust their lives to provide care while at the same time coping with the emotional implications of coming to terms with their parent's new condition.

Pedro is slowly accepting that his mother will never be the same after the stroke she had a month ago. He is slowly becoming emotionally ready for the caregiving tasks that lay ahead. The stroke left his mother on a wheelchair and resulted in a high loss of functional and cognitive level. Assuming her new health condition has been the hardest part of caring her.

> *Seeing my mom like this is terrible. She was so happy and so active; she was always talking with neighbours, smiling. She was the oak of the family. And now she is someone else, and that makes me suffer, to see her like this, I cannot accept it yet, it's too hard. (Pedro)*

Sara is 54 years old and has been caring for her mother for five years. Her mother was independent and lived on her own. She managed her life and daily activities autonomously. After her stroke her and Sara' life changed. After being hospitalised for 11 days she began to live with Sara and her family. They adapted heir house infrastructure to receive her now that she had severe physical dependency. Sara adapted her life as well. She remembers the first months of her caregiving path as the most difficult ones. She fell sick because of the pressure to adjust to her new role as her mother's carer. She used to work full time. She quit her job to, as she says, start a new life in full dedication to her mother.

Another situation that can be experienced as a difficulty at the beginning of the caregiving experience, or as the needs of the elderly change, is the lack of knowledge of the carer on how to care for an elderly person with high needs of care. For Silvia, the beginning was the most difficult stage of he caring path; she didn't feel prepared to care for her mother, who, by the time Silvia decided to take her mother to her house and become her main carer, had an advanced level of physical and cognitive dependency. The lack of knowledge and information to carry out care related tasks and to relate to an elderly in need of care, worried her the most.

> *At the beginning it was hard, I didn't know how to care for an elderly, I didn't have any idea, I used to shout at her saying 'mom you don't have to do this' or 'you have to do that' and sometimes I was very angry at her, but I never hit her, I never did that, but I said 'mom you need to understand me, you need to do what I tell you' and things like that, but right after my attitude I used to said to myself 'I shouldn't react like this because she is sick.' And then I started learning everything by myself, by intuition, no one taught me how to care for her. I said to God 'please help me because I don't have any idea on how to do this.' I now know everything, and there she is, pretty good. (Silvia)*

Being the carer of an elderly parent with a deteriorated health is experienced with difficulty by some carers who see that the death of the elderly is close. Although they would like to have a relief of their carer's role and they also want the elderly to stop suffering in this world, they also feel sad when thinking about the moment when they will leave it.

It was common for carers who have spent more than five years caring for an elderly parent or parent-in-law to feel both tired and sad about their role as carers. Tired because of the physical and emotional demands of caregiving. Sad because of the idea of their parents' death. Most carers cried during the interviews when they talked about the moment that their elderly parents will no longer be alive.

Eugenia experiences these mixed-feelings. She is the main carer of her severely dependent mother. She recognises that she does not have time of her own, but at the same time, she doesn't want her mother to leave her. She cries during the interview.

> *On the one hand, I do not have time for anything and all I want is to rest, but on the other hand I do not want my mom to pass away (crying). (Eugenia)*

Carmen wishes her mother die to stop suffering, but the thought of her death makes her sad.

> *It is very difficult (cries). I know she has to go and I pray to God he takes her away with him. I know she has to go, but it makes me sad. I know she will be better if she is no longer here because she is suffering but I don't want her to leave. (Carmen)*

Estela has spent the last 15 years of her life providing care to her mother, who is now 95 years old. As her mother's dependency level advanced, Estela began to postpone most of her activities, dedicating her days almost exclusively to her mother's care. Now, when she thinks of those days in which her mother will no longer be with her she feels sad.

> *I wonder what will become of me when my mom is gone, and it is a big source of anxiety I have. (Estela)*

ii) Dementia: dealing with a new reality

Although the functional and physical disabilities of an older person are an objective difficulty, mental disabilities are a source of worry and are difficult to deal with (OMS 2016). The potential constraints associated to the experience of caring an elderly parent with dementia are particularly important because of the increase in the percentage of elderlies with dementia in Chile, percentage that is expected to triplicate by 2050 (Gajardo and Monsalve 2014). There are currently no national policies in Chile regarding people with dementia and their carers. People with such diagnoses may present extraordinary management difficulties. They require personal care during the later stages of the disease, but they exhibit forgetfulness, incontinence, wandering, sleep disturbances and combativeness (Brody 1996).

Taking care of an elderly parent or parent-in-law with cognitive dependency with whom there is no verbal interaction, or with whom there is no possibility of a coherent conversation can be a difficult task. In addition, the lack of gratitude or recognition of the care rendered can add difficulty in everyday life. Family carers of people with dementia are often called *the invisible second patients*, because the effects of being a family carer for an elderly with dementia, though sometimes positive (Cohen et al 2002, Sanders 2005), are generally negative (Brodaty and Donkin 2009).

Florencia, Pedro, Eugenia, Rita and Antonia, among others, care for an elderly parent with advanced stage Alzheimer's. They all find difficulty in not being able to hold a conversation with their mothers as they could before. The inability to hold a conversation increases their feeling of loneliness and the sadness they feel as a result of seeing their elderly parent's health deteriorate. Antonia is fully dedicated to her mother's care, she is her mother's only child and receives no help from other people for her mother's care. Antonia cannot communicate with her mother, which is experienced as a difficulty.

> *At lunch we don't speak. I speak to her but she does not listen to me, I have to hold her hands and say 'mommy you know this or that happened' or 'I want to tell you something I saw'. But she does not care or she looks at me but doesn't even move her face. She does not say 'ah ha' or 'ok', nothing. (Antonia)*

Another difficulty carers experience caring for an elderly parent with dementia is related to accepting their illness. It is difficult even as the illness first develops. Alejandra found it hard to accept her father's cognitive deterioration and denied it at first. She preferred to think nothing was happening, until acceptance was inevitable.

Alzheimer's can render a person aggressive. This is a difficulty experienced by Lucy, Consuelo and Antonia, since they all have had to face physical violence and verbal or emotional violence.

Alzheimer's can also change a person's personality. Caring for her mother is difficult for Rita. Rita lives with her husband, daughter, son-in-law and her elderly mother. Rita is the only child and has always lived with her mother, a very conservative woman. Alzheimer's completely changed her mother's personality and Rita has had to understand and love a new person, someone completely different from whom she knew.

> *My mother has been having for a long time now a sexual fixation, which is something terrible. I use to cry and ask God to give me strength and bring my real mother back (she cries). I decided to talk about it with the doctor. I did not talk about it with anybody else because nobody else would understand, they would think she does all that [masturbate on a constant basis] because she is horny, but not because it's part of this horrible disease [Alzheimer's]. I asked my mom why she does it, and she said she hadn't done anything, but she was all wet, I had to change all her clothes. I took out all of her bedroom [objects] she can use [to masturbate]. She is now under a strong medical treatment and is supposed to sleep deeply, but no, that's not the case [it doesn't*

> *work]. During the day I tried to see if she is awake. I turn the TV on and put it loud, but she puts it quieter and closes her bedroom's door. There are so many things I don't understand about her behaviour… My mom used to be very conservative, she never said bad words, she was conservative in the way she dressed, she talked, in her attitudes, and now [she pauses and cries] now I barely recognize her. (Rita)*

On the contrary, Adela sees her experience of caring for her mother with Alzheimer's disease as an opportunity to get along with her mother, whom now has a totally different personality and has lost most of her cognitive capacity. This is a case of a complex mother-daughter relationship. Adela and her mother always had a difficult relationship when her mother did not have dementia. For Adela dealing with her mother now that she has changed her personality is not a very difficult task. She sees it as an opportunity to be close to her mother after a long history of distance. Chapter 7 addresses the relevance of the historical relationship between the carer and the elderly to explain why difficult situations – like caring for an elderly with dementia – may contribute to understand why it is, or not, considered a constraint.

6.6 Formal support

Another situation in carers' life that could become a constraint or a resource has to do with the existence, availability, accessibility and acceptance of formal public and private services of support. Formal support is the help provided by professionals, paid helpers, or companies who provide caregiving, governed by contractual rather than affiliative norms (Miller et al 1994). This section describes carers' situations related to the existence (and participation in) or absence of formal support with attention to those situations that are experienced as constraints or resources. The following situations are described in this section: 1) the disparity of services offered by different municipalities, 2) the limits of programmes that provide respite, 3) the timing of programmes that give information on how to care, 4) the lack of public and private resources for middle-income families to access formal care support, 5) the difficult decision to opt for institutional care, 6) the support offered by primary health care centres and hospitals and 7) the support from paid caregivers.

6.6.1 The disparity of services offered by different municipalities

In Chile, and as described in Chapter 4, municipalities are largely in charge of providing social services, some of which will offer support to carers. This support is not equally distributed among municipalities, meaning that, depending on the municipality of their elderly parent or parent-in-law's residence, not all carers will have the same access to carer support programmes. Municipalities in Chile are very unequal in terms of their resources and services because a majority of their funding comes from property taxes and Chile has high levels of residential inequality (OECD 2015b). When they exist, most care support programmes are targeted to the most economically vulnerable population, excluding middle-income households from coverage.

Carers in municipalities that do not offer any support or that do not meet eligibility requirements experience a first constraint in the fact that they do not receive any public support and a second in experiencing non-universal access. Ineligible carers or those in service-deprived municipalities are aware that other people in similar situations to their own do access support just because they live in a different municipality or are categorised as vulnerable and would like the same for them.

As noted in Chapter 4, The *Servicio Nacional del Adulto Mayor* (SENAMA, National Service for the Elderly) offers funding for municipalities to implement social care programmes. Municipalities have to apply to SENAMA to receive funds to implement SENAMA's programmes, and in some cases complement SENAMA's funds with their own to get the programme running (this is a constraint for many Municipalities struggling with limited budgets). Municipalities' offer of social care services depends on the willingness of those working in the municipal offices for the elderly to apply for funding, on the political interest of the mayor to pursue the interests of the elderly and on the chances they receive funding from SENAMA.

SENAMA sponsors three elderly-care programmes: *Cuidados Domiciliarios* (Home Care Programme), *Establecimiento de Larga Estadía para Adultos Mayores* (Elderly Residences for Long Term Care, ELEAM) and *Centros Diurnos para el Adulto Mayor* (Day Care Centres for the Elderly) for elderlies with low dependency level. These programmes and the Chilean context is explained in detail in Chapter 4.

In this study, there are carers who have access to some programmes and activities offered by their municipalities, while others do not have access to these resources. For these latter, inaccessibility to public support was a constraint especially for those from middle-income households who do not meet eligibility requirements nor have the money to externalise part of the caring duties even though they are open to delegating care duties for at least a couple of hours a day.

Antonia is an only child and lives in a middle-income household. She cares for her 98-year-old elderly mother who has cognitive dependency. She stopped working as an independent dressmaker because she didn't have enough time to meet her mother's care demands. For her, living in a municipality that does not provide social support for elderly care is a constraint. She sees the difference this kind of support can make in carers' experience. Two of her friends are sisters caring for their cognitively dependent parents, but, as opposed to her, they live in a municipality that provides support. Antonia says the availability of this support is one of the reasons why their experience is better than hers.

> *I have a pair of friends who have their mom and their dad with Alzheimer's disease. They are two and they live with their parents. They also remained unmarried... I know that caring for two persons with Alzheimer's disease is exhausting, but when I called them they always seem happy, maybe because they are two and they are together and have other brothers, two of them are married and come to see them and give them money to buy diapers. More importantly, they live in a municipality in which they care more for the elderly. From the beginning they were very supportive, they gave them diapers and a special bed, and a lady goes once a week to give their elderly parents some exercises. (Antonia)*

Carers living in an area where the municipality offers social programmes for them and the elderly positively value that support. Low-income carers who participate in the *Cuidados Domiciliarios* (Home Care) programme[76] were satisfied and mentioned that the two hours of support received per week is enough. They were more enthusiastic about the material support (money or devices given by the primary health centre), than about the offer of direct care for the elderlies and the consequent respite offered.

The supportive role from social programmes may be more symbolic: two hours of care and a small monetary compensation may provide little respite in the way of alleviating economic constraints and work-related pressures, but it may be appreciated by carers as a social recognition of the caregiving work.

> *We [carers] are invisible. You know, people take care of the sick people but not of the family carers... this is an invisible world. (Mauricio)*

For Mauricio, the fact that someone is aware of the investment he makes for his mother's care is a positive factor in his life.

Also, the satisfaction carers get from formal public support is related to the perceptions they have towards their role as a carers, how care must be rendered and by whom. For example, if a carer thinks that it is his or her role to care for the elderly, external help will not be as welcome as when the main carer thinks it is a collective responsibility to care for the elderly.

Issues related to carers' perception of caring and care ideals, will be discussed in a following chapter. They are important to consider, as without proper understanding of a carers own role perception, it is difficult to understand their experience with respect to formal public support.

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[76] The *Cuidados Domiciliarios* (Home Care) programme was designed by SENAMA with the objective of improving the quality of home care through the provision of respite to carers and training community members to become carers and offer respite. These communal carers are required to be at least 18 years old and have completed eight years of formal education. They replace the family carer once a week for two hours and the carer receives between 15 and 23 euros per month for every elderly they care. The coverage of this programme is limited to carers of severely dependent elderly belonging to the most disadvantaged socioeconomic groups in municipalities offering the programme (as per the national socioeconomic characterisation *Ficha de Caracterización Social).*

6.6.2 The limits to programmes offering respite

Socioeconomically disadvantaged carers who participate in the *Cuidados Domiciliarios* programme value the respite they receive even though the programme only provides externalised care for two hours a week. Carers found it was enough time, which contrasts with the generalised desire among low- and middle-income carers in the sample for more time for themselves. Support for respite is welcome, but has limits.[77]

Isabel and Paz provide all care with little or no support from friends or relatives. Isabel is the main carer of both her elderly parents; Paz is the main carer for both her parents-in-law. Both women are beneficiaries of the Home Care programme in their communities. They are both happy with the weekly visits of the external carer and they consider that the time provided is enough. More frequent or longer visits would imply a feeling of invasion by the part of a person external to the household, of giving something personal away to someone that is not trusted enough. Both Isabel and Paz mention that the limits to more respite lie in elderlies' willingness to interact with different people. Isabel says it's her mother who doesn't like having strangers at home. Paz says that the elderlies get tired because they are not used to interacting with *'people from outside'*.

> *The woman's visit every Tuesday alleviates me a lot, because during that time I am not obliged to be aware of how my parents are doing, nor do I need to sit down with them and watch television. I can do other things that had accumulated, home tasks that accumulated for days. I think it's fine like it is, more visits would be a little annoying because it means having someone from the outside inside your house, and specially my mother is not very keen for that. (Isabel)*
>
> *There is people coming from the municipality once a week and I am happy because they [her elderly parents-in-law] see another face, talk about other things, if they have to complain they complain to someone else... While the lady is here I do my stuff, sometimes she calls me and I have to be there and we talk. I think that the programme is fine, but I don't want they come more often because if they come more often they (the elderlies) get tired because sometimes they don't like it that much, and it's logical because they [the elderlies] are people from the countryside and it's tiring to have people from outside all the time. Although when the lady is here they have a good time, and I am happy because they see other faces and there is someone else that give them love. (Paz)*

6.6.3 Timing of programmes that provide information for carers

Other public support programmes and initiatives for carers provide information about how to care for the elderly and information on how to care for themselves. These programmes can be less a resource and more a constraint in certain cases, increasing carers' pressure. They are a

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[77] As will be seen in a following section, the self-perception of a carer's role and the reasons for assuming the caregiving role influence the extent to which carers are willing to externalise care and receive support.

resource when they are provided at the beginning of the dependency path, when carers are just starting with their role and they lack the knowledge on how to render care and to care about themselves while being an elderly carer. For carers who have provided care for a long time and have settled into a routine and a way of going about their tasks, the information received in these programmes can lead to frustration and guilt if the information is not aligned to their way of doing things.

Both Rodrigo and Antonia participated in information-provision programmes after caring for their parents for an extended period of time. They both came out of the programme worried or sad knowing that the things they had been doing to care for their parents were not correct. The programme created sources of pressure.

Informational programmes and initiatives are better for carers at the beginning of the dependency path. Alejandra is satisfied from participating in a programme that provides caregiving information. Her father was diagnosed with Alzheimer's two months prior to the interview. Since then, Alejandra and her husband have participated in a municipal programme for carers of elderlies with cognitive dependency, *Cuidando al Cuidador* (Caring for the Carer). Professionals who teach it come from a mental health outpatient community centre (COSAM) that supports and complements the community's primary health care centre.

> *We understood what Alzheimer's disease means, we understood that you have make my daddy participate in everything, that we don't have to leave him in a corner, do not tire him and that he must participate in our daily life. Often the main carer does not know how to do things. The course is very good for people who are ignorant on the subject, for those, as myself, the course is excellent. At the end they will give us a booklet with all the information they have given to us along the course. (Antonia)*

Antonia also participates in the programme *Cuidando al Cuidador*. She joined after her mother's Alzheimer's developed, but she had already been her main carer for several years. The information provided in the programme generated pressure and anxiety. She had been doing things differently for a long time. She felt many of the suggestions the instructors made to promote carer's wellbeing did not depend on her at all.

> *I told the COSAM instructors 'how much time have I lost, how much tiredness thrown'. I told them the other Thursday 'I would have liked to have heard all of this five years ago' and they said that it is never too late but for me it is too late because I'm already exhausted. I've come home very upset after some of these Thursday courses. I come back upset. For example, the other day we talked about the support that one should receive as a carer, supportive networks we should have, there were three: family, friends and co-workers, I don't have any, but not because I don't want to, I just don't have them, I am not that lucky, I have no family or friends or co-workers... when it was my turn to speak I said that I don't have any of them and they insisted that it's never too late. (Antonia)*

A positive aspect of these programmes is that they alleviate the carers' daily pressure by giving them a space to meet people and socialise. It also allows carers to leave their house, change theirroutine and see new faces. They see others in similar situations. Realising that their situation is not unique lessens the feeling of pressure.

For carers who have provided care for an extended period of time, the value of participation in these programmes is the realisation that they are not alone and that many people share their difficulties.

> *Doctor Ahumada, from the primary health centre, invited me to a course for family carers of elderly people led by nursing students from Universidad Central. I missed two or three classes, but it was very interesting, but I found out one thing, well there was too much of how things should be done, like how to give a bath to the elderly, how to move them, etc, but in the end we kept doing things the way we have always done it. I know there are movements that I should not do because they make me have back pain but the truth is that you get used to doing things one way. In any case the course was worth it and the best of it was the relationship we had between the participants, because seeing other people who had similar lives that yours and maybe worse problems served as relief, 'I am not the only one on this'. (Rodrigo)*

6.6.4 Middle-income families lack public and private resources to access to formal care support.

Most public policies in Chile are based on a focalised principle. They are not universal. They target individuals and households in the most vulnerable social and economic situations. Public social care policies are no exception. The middle class, the largest in terms of population size, has to solve their care needs privately; middle class households often do not receive government support for social care (or other forms of support thereof). Moreover, middle class households do not have the economic means to access the market for the provision of care services (see Chapter 4).

The middle class relies on what they and the care recipient consider to be the most functional and least expensive alternative (Acosta 2013). They often rely on non-paid informal care arrangements with care provided by female family members. The growth of the female labour force participation in the last decades and the consequent growth in the size of the middle class in Chile have not brought about a redistribution of care within the household or a strengthening of the public delivery of care (Arriagada and Sojo 2012).

Fátima is 46 years old and is the main and only carer of her 85-year-old mother with a medium dependency level. She is the youngest of five siblings. She is married, has two sons and a daughter. Her husband works as a school principal. His income is enough to qualify the household as a middle-income household. Fátima's mother receives a monthly basic solidarity pension (around 135 euros) and is enrolled in the public health system. As a middle-income household, neither Fátima, her mother nor the household receive anything else in terms of public support. Fátima has been out of the labour force since her children were born. In the case she wanted to have a paid job, having been out of work for so long would only make her eligible for jobs that do not pay a good enough salary to pay for an external carer. Fátima is stuck in the middle: she doesn't have the means to externalise care and she is not eligible for public help. She thinks it's unfair and strains her.

> *I have asked more than twice in the municipality if they can support me in any way. My mom, she receives her basic pension and that's it and I... (Fátima stops the phrase and looks frustrated) But I don't qualify to any kind of help because I am under my husband's health insurance and it's the household income that counts for receiving support, not the individual income. But as I can't work because I have to stay at home caring for my mom I don't have any personal income and additionally I don't qualify for any help from the government. I can't even be attended in the primary health centre. (Fátima)*

Ofelia has worked for 37 years as a teacher in a school for deaf children. She is a middle-income worker and the main carer of her 89-year-old father. Her father used to receive a pension from the private individual-savings accounts system (AFP) but his private account no longer has any funds. He now receives a basic solidity pension from the government. Ofelia is upset about her situation. She doesn't like leaving her father alone while she is at work, because his frailty is increasing and he has started to lose his memory. She would like to stop working and stay at home with her father, or would like to be able to pay someone to help her with her father's care while she is at work. If she stops working her pension wouldn't be enough to maintain her living standards (although they are not high) nor is her salary enough to pay an external carer.

> *Look, I don't want to work any more and the most important cause of that is my father, because I don't want to leave him alone every morning. It gives me a headache, it worries me, makes me tense, it gives me anxiety. At school I am always busy but when I think about my father I worry. At this stage of my life, after 37 working years I want to give up, I am tired. The problem is that if I stop working I will receive a pension of 250 thousands pesos per month [around 360 euros], it's a shame. So, how can it be if I have studied and worked my whole life? I have never stopped working. It's unfair, it makes me angry, angry at our society, a society that hasn't advanced in that sense. (Ofelia)*

These two middle-income carers struggle because they don't have enough monetary resources to externalise care and need to work even if they are tired or would prefer to quit and become full-time carers. They need to work to maintain their middle class living standards, but their income is not high enough to externalise care. The conflict is that they need a source of income but also feel the need to provide care. These two pressures cannot be reconciled.

6.6.5 The difficult decision to rely on institutional care for the elderly

Almost all cases from the sample stated that institutional care is not an option for their elderly parents or parents in law, irrespective of their household income.[78,79]

While institutional arrangements for elderly care may contribute to reducing the carers' direct-care obligations, they do not necessarily reduce carers' constraints (Brodaty and Donkin 2009). Relief and stress reduction may follow institutionalisation (Aneshensel et al 1995), but so can guilt, anger, depression, and financial problems (Tornatore and Grant 2002).

Only two cases in this study were the main carers of an elderly living in an institution (Cintia and Ana María). Florencia had her mother in an institution and then decided to take bring her to her home. Ana María comes from a high-income household; Cintia from a low-middle-income household. Both Cintia and Ana María were happy with having their elderly parent or parent-in-law in an institution, and avoiding cohabitation. It was not easy at first. Cintia is the main carer of her mother-in-law and had been her deceased mother's main carer who had severe dependency for 20 years. Cintia is 65 years old, she has a husband who is an only child and two brothers. Cintia paid an external carer to care for her mother during the day on weekdays. On the 14th year, Cintia had to take a year on leave without pay from her work because her mother was increasingly frail and no external carer was willing to care for her for the salary Cintia could pay. She thanks God for the chance to leave her mother in a nursing home sponsored by the Catholic Church.

At first, the idea of leaving her mother in an institution was scary because nursing homes for the elderly, especially those available for low-income families, do not have a reputation for giving a good quality of care to the elderly. Cintia first took a few weeks off of work and spent the time working as a volunteer in an elderly nursing home close to her house which as recommended by two of her colleagues, to see the elderly care conditions in place. She was pleasantly surprised with the living conditions of the elderly people there and took her mother there. When her mother-in-law was diagnosed with Alzheimer's, Cintia and her husband decided to take her to the same nursing home. She is happy with the arrangement.

Ana María, from a high-income household, is the main carer of her cognitively dependent mother. She has two brothers and a sister who lives abroad. Her mother used to live in the countryside, four hours away from Santiago. In 2008, her mother had a stroke and began losing

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[78] Institutional care for the elderly or nursing homes in Chile are called ELEAM (Institutions for Long Stay for the Elderly). ELEAMs are usually managed by non-for profit organisations (most of them are faith-based institutions) but some for-profit ELEAMs exist. In the former cases, the elderly pays a monthly payment according to their family income, in the latter, prices are set according to the functionality profile of the elderly and their room preferences (single or shared room).

[79] Chapter 7 discusses the reasons why carers are wary of institutional care for their elderly.

her cognitive capacity. Her father was also sick with a kidney disease that required daily dialysis at home. They were under the direct care of two nurses, and Ana María visited every other week to organise their care. In 2010, Ana María's father died and her mother's health deteriorated and required Ana María to be closer. Her mother would call her by phone *"come visit"* or *"come here it's an emergency"*. Ana María decided to have her mother live in a nursing home. Ana María had a hard time at first. She felt guilty of not taking her mother to live with her. Today she is convinced that it is the best arrangement for both of them.

> *Well, then I realised that this situation was crazy: she living there and I living here in Santiago. I had to bring her here and there was the problem of where. I then started looking for places, because I couldn't take her to my home because she does not get along very well with Mauricio [her husband] and I cannot impose him to live with my mother, so I had to look for places (she cries) that was very hard, very, and finally I did. I spoke to my brothers, they gave me all their support, because at first it was hard to convince them, but this issue was getting super hard on me and I could not continue traveling that often to San Rodrigo [were her mother lived]. My sister came from the United States and helped me with the move… It took her a year to get used… And now for me it is much more bearable. Well, there are always problems, but I have friends who have their mom in their house and it is a tremendous thing, tremendous for marriage. (Ana María)*

Florencia, used to have her mother in an elderly institution. Florencia decided to take her out because she did not receive adequate care. Her mother lost weight and had recurrent falls. In addition, Florencia was spending almost all her salary on the institution, so preferred to quit her job and have her mother at home under her care.

All other cases of the study showed a categorical rejection towards the institutionalisation of the elderly under their care. Institutionalised care does not conform to their ideas of what appropriate care is. This will be discussed in Chapter 7, since it's intrinsically related to the motivations to provide care and to their perceptions towards their role as carers.

6.6.6 Primary health care centre and hospital support

Most social support programmes in Chile are means tested. However, under the GES plan, the health system offers universal benefits for the health problems that cause most deaths and are more prevalent among the population.[80]

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[80] This is a programme designed and implemented by the Chilean Ministry of Health. It is a set of explicit guarantees on right to health care for the entire population. It ensures medical coverage for health problems that cause most deaths, regulates waiting times by law, regulates the amount of co-payments to financially protect families, and regulates quality standards. Access to these benefits is independent of the income level or age of the beneficiary.

Carers from middle-income families and from low-income families mentioned the importance of the support from primary health centres. Low-income families valued the support in terms of care supplies, such as medicines, wheelchairs and medical beds for the elderly.

> *We received the wheelchair, and we are often there (in the primary health centre). The centre is near here, there is one a few blocks away. They always welcome us, they give me most of her [her mother's] medicines, and all the medicines for her diabetes, from time to time they do other exams, we see the doctor there, the nurse. And the rest of the medical health attention we receive is in COSAM,*[81] *there is a psychiatrist that prescribes sleeping pills, the pills to keep her quiet and everything else. (Rita)*

Having a good relationship with the primary health centre doctor was important for carers who have one. The doctor is a reference for them. Three interviewees that live in the same community and were registered in the same health centre mention the importance of counting on the primary health centre doctor. They all highlight how grateful they are with this doctor.

Elderlies with severe dependency receive visits from the doctor or health professional in their own place. Carers of severely dependent elderly do not have to take the elderly to the centre, which avoids the strain that transportation causes.

Carers who live far from the primary health centre don't go there often. They can't count on it for more support than going for the medical visits. Using public transportation to reach the health centre with an elderly in need of care was a common cause of worry for carers. For carers, public transport is not well adapted for elderly people. They can get very crowded, increasing the likelihood of a fall. Taking a taxi is too expensive for some carers.

Though usually a resource, primary health centres and the public system in general suffers from long waiting lists for surgeries and consultations, inability to choose the doctor providing care and inability to choose the location of care provision. Appointments need to be made in person, making it necessary for carers to arrive among the first in line at 6h, as appointments are set by order of arrival. This situation brings many difficulties for carers because either they have to organise their family life before leaving that morning or they have to leave the elderly alone for some hours while they go to the health centre to make the appointment.

Worrisome situations with the public health system were also observed in hospitals, when carers from middle and low-income households brought the elderly following a health emergency. Usually, the attention in the public hospital was not what carers expected for their elderlies. Eugenia, from low-middle income household, took her mother to a public hospital after she fell and fractured a hip. At the public hospital there was no bed availability, so they sent her mother to another public hospital. Not receiving a good attention in the second hospital, Eugenia took

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[81] COSAMs are outpatient community centres for mental health that supports and complements the primary health care centre of the communities. They belong to the public health system.

her mother to a private hospital, with the implication that it took her and her siblings three years to pay for the bill.

Carers from high-income households never mentioned the support of primary health centres or expressed concerns with experience in public hospitals because they do not use them; they go directly to doctors in the private health system. High-income carers can avoid the downside of the public health system (long waiting lists, inability to choose the doctor, location not always convenient, etc) by paying more.

6.6.7 The support from paid carers

Paid carers provide direct care and sometimes also emotional support to the elderlies in need of care. The effect of the externalisation of care on carers' experience will depend, at least partly, on whether externalisation is considered a well-deserved respite for the carer or a response to a lack of commitment (García 2010). In the study there was no mention to feeling upset, guilty or irresponsible because the main carer was delegating caregiving tasks.

In the study, there are two types of external paid carers: nurses and nursing technicians, on the one hand, and people with no formal knowledge on elderly care (e.g. domestic service and maids), on the other. The experience the main family carer has with these two types of paid carers differs significantly.

In no case in the study was the family carer satisfied with the support received from nurses or nurse technicians. On the contrary, most carers who count on the support coming from other external carers expressed more satisfaction with the care arrangement and the support they receive from the external carer. These are paid carers without formal knowledge on elderly care but with knowledge acquired through experience and, importantly, shared trust with their employer and the elderly in need of care. In all cases, however, support from external carers was not free of obstacles. This section develops the two major obstacles for caregivers regarding this issue: i) the fact that professional carer support is expensive and requires management and ii) the difficulties in finding a trustworthy non-professional carer that provides stable support.

i) Professional carer support is expensive and requires management

Three of this study's carers had nurses or nurse technicians caring for their elderlies in need of care. The three cases pay a company that sends nurses or nursing technicians to care for the elderly. Clients pay the company and any complaint is directed to the company. The system is not free of difficulties: they mention that nurses are not prepared for elderly care nor prepared to work in the intimate and personal environment of a family's home or to deal with the human relations of such an environment, especially in relation to maids and other domestic service. Also, nurses and nurse technicians rotate, so clients do not, necessarily, have the same nurse all the time. Trust is important in the personal setting of a person's home and in carers' decision to externalise care. It is hard for main carers to trust nurses and technicians that change all the time; trust can be bestowed on the company that coordinates the service, but carers expect trust with the nurse, not necessarily the company.

Marita used this system of nurses, but changed after she became unsatisfied. Rebeca, Josefina and Aurora, all from high-income households, use it for their severely dependent elderly parents. The three women mention that, even though they have a good financial standing, this system is a very expensive solution for their parents' care.

> *The truth is that the nursing system in Chile is horrible. First, there is a social thing, the nurse feels superior to the domestic service and is always making a difference... Nurses are so poorly trained, poorly controlled, I'm talking about home nurses… The general training of a nurse is very, very poor, both in geriatrics and in human relations, especially with a tough attitude to live in a family home… (Josefina)*

The three women who used this system claim that dealing with nurses was an important issue in the general difficulties they faced with their elderly parents' care. As mentioned earlier, the supervision of paid carers implies managing conflicts between nurses and domestic service. In these high-income households, nurses are responsible for the direct care of the elderly, while the domestic service takes care of the household issues, but these distinctions are less clear in practice.

ii) Finding a trustworthy non-professional carer and wishing he or she will render stable support

Other family carers externalise care duties on non-professional paid carers. The presence of paid carers can add pressure to the care experience (Soulier 2012), opening the elderly's home to non-members generates a sense of loss of control of the process of care, greater insecurity and a feeling of pressure (García 2010). Trust on the paid carer overcomes these feelings. All carers in this study who externalise care on paid non-professional carers mention the time they have known the hired person, or the recommendations received from close acquaintances before hiring. For example, Elisa said proudly in the interview that she has known the woman that helps her with her mother-in-law's care for 20 years. Pedro also has an external caregiver.

> *We know this girl since she was young. Her mother was a friend of my mother and when my mother had the stroke she offered to help her, and I talked to my sisters and we decided to give her a monthly salary. (Pedro)*

Adela's mother stays with a neighbour while Adela is at work. Adela's brother knew the man.

> *He is an excellent man that lives in our neighbourhood, a couple of buildings from here. I met him through my brother. He is an Evangelical pastor. (Adela)*

Family carers acknowledge the difficulty in finding a trustworthy external carer. They are afraid of the possibility that their paid carer might quit. The presumed instability of external support is a constraint for carers, as is the case for Estela.

> *Before it was a lady, Sandra, who helped me, but she got sick and stopped working. My sister-in-law helps me now. The thing is that it's difficult to have strangers in the house. I have to run errands and leave my mother with a stranger. I don't like that at all, it worries me. My sister-in-law lives upstairs and she comes down every morning to help me. I pay her 200 thousands pesos [285 euros]. She helps me with lunch, with cleaning, and watching my mother so I can get out of the house and run errands. My only apprehension is that one day she will tell me that she has decided to stop helping me because she is tired, because she is already 76 years old, so she gets tired. (Estela)*

Estela is not comfortable with having a person she doesn't know helping her with her mother's care.

For Marita, one of the most difficult parts of being her mother's main carer is what she calls the *'externalisation issue*'; the fact that she cannot trust paid carers immediately.

> *[It] limits my life in many aspects, but look, everything has a good and a bad side. Now I have less freedom to move and to do my own things because I have to be watching for carers closely every time a new one arrives because it's not that I can leave them alone right away when they arrive. (Marita)*

She also refers to the strain she feels every time a hired carer announces they are leaving, something that has happened often with the Peruvian women she has hired. Fortunately for her, Peruvian immigrant carers are a tight network and recommend each other if they have to leave.

> *The one [Peruvian paid carer] who took over [her mother's] caring duties became pregnant and left on this 'famous prenatal leave' and left us with another women from Peru who was recommended because she had previously taken care of an elderly in Peru before coming to Chile. A month ago she had some health problems and wanted to go back to Peru to get treatment close to her relatives. Before she left she recommended another Peruvian women and she taught this women a little bit how to care for my mom. It was supposed to be a replacement that was going to last until she came back from Peru [after treatment], but she called me a few days ago saying that she was not feeling well and decided to stay in Peru and is not coming back. Thank God the other woman told me that she could stay with us. Then we also have a woman who comes from Friday to Sunday to stay with my mom, while the person that is here during the week does not work. (Marita)*

6.7 Support from social networks

This section describes the informal support carers receive from their social networks, including relatives, neighbours and the religious community. Carers' experiences are not indifferent to the support they receive or the one they would like to receive. As in previous sections, the existence of informal support can be a resource, but also a constraint. How carers experience this support will depend on what they consider a legitimate source of care and the legitimate excuses for not providing care by members of their social networks (e.g. siblings). These expectations will also interfere with the relationships carers have with members of their social networks (e.g. relatives). This section then, describes how members of kin and other people including neighbours and the religious community provide support, from the main carer's perspective. The absence of support by the part of family members is also addressed.

How relationships, perceptions towards the carer's role and biographies interfere in how carers perceive support will be analysed in Chapter 7, after exploring carers' emotions in more detail.

Support from family members, as well as from friends and neighbours, is typically referred to as informal social support (Williams and Dilworth-Anderson 2002). Social networks are not equivalent to social support. Social networks are the vehicles through which social support is distributed (Keating et al 2003). Social support is the assistance to people and groups from inside their communities, which could be useful when facing and coping adverse conditions in life. It can be, but not necessarily is, a resource for improving quality of life and wellbeing (Otero et al 2006). Social support comprises different components. It can take the form of instrumental assistance, emotional support, affirmation and companionship (Abel 1991). Although the social network and social support usually have a fundamentally positive character, they do not always equate to greater wellbeing for the person with care needs or the carer. A wider social network can be detrimental to the efficient performance of the care activity, because it can be a source of intrusion, bad advice and conflict, rather than a source of help (Lefley 1997). Social networks are not converted automatically into social support (Abel 1991). Generally, a larger social support network is considered preferable to a smaller network (Williams and Dilworth-Anderson 2002). However, large size could also be problematic (Lockery 1991).

The following sections describe the following situations of social support in caregivers' daily lives: 1) the religious community and the faith in God and 2) family (siblings, children and partners' support) and neighbours'suport.

6.7.1 The support from the religious community and the faith in God give strength to carers

The religious community offers one avenue for receiving social support. Participation in a religious community offered carers a space for respite from caring responsibilities, a space to meet and share with other people. Support from the religious community takes the form of a space for respite, of emotional support and also through the development of faith, which offers support as well. Social support from a religious community appeared more often among carers who were an only child and among carers who received very little or no social support from relatives and friends. The religious community complements social support and replaces lacking social support. However, active participation in a religious community may not be compatible with caregiving duties if the elderly has moderate or severe dependency. The lack of free time or support while attending services or activities was an impediment for religious carers to participate in the religious community.

Antonia is the only child and the main carer of her cognitively dependent mother with whom she does not have a good relationship. Apart from religion she does not receive any other support. For her, caregiving is experienced with a high degree of pressure. The religious community is her only source of support.

> *In the end I think that my only support has been my religion. I go to mass and I talk to the priest and I tell him about my worries and anxieties. He says I should better not think about my situation, that I should leave it in the hands of God. That's what helps me the most. (Antonia)*

Elisa, 48 years old, is the main carer of her mother-in-law. Elisa is the mother of seven children (all under 15 years old) and comes from a high-income household. She goes to church every morning after her children leave for school. This daily routine is like a therapy. It offers her a space to meet friends, think about something different than her caring role and regain strength.

Pilar, a 61-year-old middle-income carer receives strong support from her sister and highlights how her religious community is important to her. She goes to church weekly and participates in a few activities that give her respite from care. Her faith in God is also a strong source of support for her.

> *I believe in God, I'm always praying and asking God to give me health and strength to care for my father. (Pilar)*

Isabel is 51 years old, from a low middle-income household, and her father's carer. Violeta is an only child, she is 62 years old from middle income household and caring for her mother. For both Isabel and Violeta, religion offers support.

> *Look, the Lord gives us strength, He is my company… I ask for Divine help, I ask the Lord every day to give me patience and understanding. (Isabel)*

6.7.2 Family and neighbours

Family members and neighbours are another source of social support for caregivers. This section develops the specific sources of this support, such as i) siblings, ii) children, iii) partner and iv) neighbours.

i) Sibling support

Siblings can participate in the elderly care arrangement and give support to the main carer in different ways: *back up help* is the predictable support carers count on from siblings, especially sisters; *circumscribed help* is predictable yet bounded such as help with financial tasks, characteristic of brothers; and *sporadic support* is help given at the provider's convenience and is not seen by carer as significant in meeting their parents' needs. The reliability of support can range from *dissociation*, when a sibling cannot be counted on to *routine support* when support is provided regularly and predictably. Dissociation is more common among brothers but also occurs with sisters; sisters are more likely to provide *routine support* (Matthews and Rosner 1988). Within a family, different siblings offer different levels of support. The lack of support can be legitimised on the basis of gender, employment, age or health. On other grounds, the absence of support can lead to family conflict.

Catalina, the main carer or her elderly mother with whom she lives, has two sisters and three brothers. Her brothers and sisters provide different forms of support to her with their elderly mother's care. Catalina is the main carer; she provides *routine help* to her mother. Fernanda offers *back up help*. Alexander offers *circumscribed help* by giving money for his mother's care. The twin brothers offer *sporadic support,* they do not live in the same city and they come once in a while to Santiago and visit their elderly mother.[82] Grace, the eldest of the phratry, is dissociated, she does not give any support at all.

> *Fernanda gets in and out of the house, she is intermittent with my mother's care, she comes and goes, but if I need her she will be here and I can count on her. Alexander, is the Chilean consul in Vancouver and has been living in different countries. When he comes to Chile he tries to be as much as possible with our mother, he gives some money, although not much, every month. Then the twins are quite independent, they live in Punta Arenas with their own families, and curiously they are now more concerned about our mother nowadays. Once in a while they come visit her. Grace is the eldest, she never appears, she has a bad relationship with my mom and I understand her because my mother was not nice to her. (Catalina)*

Having more siblings does not necessarily mean that there are more people willing to participate in the elderly care arrangement or offer support to the primary carer. There are numerous families in which no one other than the main carer participates in the elderly care arrangement; there are big families in which a large number of the siblings are involved.

María is the main carer of her 98-year-old mother with whom she lives. María has eight siblings (five sisters and three brothers). Of all her siblings, one was involved in their mother's care for a couple of weeks in the past; another sibling helps in the present. Her eldest sister cared for her mother for a few weeks when, as the result of an accident, the mother had to go to the primary health care centre daily. It was more convenient for her eldest sister to take responsibility, as the

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[82] It is interesting to notice that carers in the study often complain that their elderly parent has a special closeness and admiration to those males in the phratry who provide sporadic support. Carers themselves do not value sporadic support very much, but apparently, elderlies do. It seems there is a disconnection between engagement in the elderly care and the recognition the child receives from their elderly parent (from the main carer's point of view).

primary health centre is just in front of her place (María has to take two buses to get to the primary centre). Another sister goes weekly to clean her mother's house.

> *She helps me with that [cleaning her mother's house], and sometimes I take my mom with us because she likes to go to her house [she no longer lives there, she lives now in María's house]. But that's all. No one, no one, helps me. I do everything and I carry with everything. But it's ok, it's not a big problem for me, because I have brothers and brothers are not useful, sisters are more useful and my sisters work and have their own life. Sometimes I think it is unfair, but it's not such a great problem either (María).*

Only eight cases in the study (out of 42) affirmed that sisters were supportive with the elderly care. One of them is Pedro, who externalises part of the caring tasks and receives support from his two sisters. His sisters stay with their parents on weekends. Paula, another carer, has four sisters with whom she shares most of the caring tasks (her brothers *do not count* because they are men). Carmen, the main carer of her severely dependent mother with whom she lives, receives the support of her two sisters who visit daily to help her providing direct care to her mother and also company and moral support to Carmen. Among Josefina's siblings, brothers and sisters included, they all share their parents care responsibilities. Both elderlies live in their own place and have 24-hour assistance provided by nurses. Josefina and her three siblings are in charge of their parents' care organisation, management and emotional support, they take turns and each sibling is in charge of one whole week.

Colomba is the main carer of her elderly father with whom she lives. Her only brother offers *back up* support. He cooperates economically with his father's care and is also attentive to Colomba's needs, her situation and anything she might need. He visits Colomba and his father often (the two live together).

Colomba is practically the only case (the other is Josefina) in which a brother gives this kind of support to the caregiving sister. In all other cases, brothers' support was mainly *circumscribed help*, usually financial. Colomba recognises gender is not a source of care-related inequalities in her family because among her parents there were never gender-related distinctions when it came to family or employment roles. Both her parents were University professors; they worked the same quantity of hours, earned the same salary and divided their children's caring tasks equally. This is a unique situation, especially considering that Colomba's father is 84 years old and gender inequalities were stronger in older generations.

Paid employment is, as gender, also considered a legitimate excuse for siblings to not provide support. Carers also excuse their siblings if they are old or if they have bad health.

A bad relationship between siblings will arise when the excuses siblings give for not providing support are not legitimate in the eyes of carers. More about the way caregivers feel about the support or lack of support they receive from siblings will be discussed in Chapter 7 when analysing the relationships between main caregivers and the rest of the family, or when analysing the reasons for becoming a carer. Carers justify, in some cases, their role as main carers of the elderly parent or parent-in-law in that other siblings have legitimate excuses for not assuming the caregiving role.

Support from siblings can also take the form of moral support. Women wanted members of their family to recognise the value of their role as carers, not just help them deal with problems associated to caregiving. For Consuelo, for example, the heaviest part of the caring experience is the lack of recognition from the extended family. She would appreciate her sisters–in-law expressing more gratitude and greater understanding over what she does. If she would be able to go back and take the decision of becoming her parent-in-law's carer, she would decline because it is work that receives little if any recognition from the rest of the family members.

> *If someone asks me now if I would repeat this I think I would say no because as a family it is an ungrateful experience, because people say 'oh you are not giving the elderly the proper food, or this or that'. But in reality you do all that, and you do it the best you can. But there is always someone that complains, that criticises how you care, no matter if you do it right or wrong. That part is very dull... (Consuelo)*

Indeed, the lack of support from siblings becomes a major source of conflict for carers. This issue will be discussed in further detail in Chapter 7 which is dedicated to relationships, as it is a major issue determining the caring experience.

ii) Children'support

In most cases, carers don't want to ask their own children for support with the elderly care. Carers believe it's not their children's role to become carers and that it's better for them to concentrate on their own affairs, be it their studies, their work, or their own nuclear families. This belief is present irrespective of carer's income status, their age or their gender. Though they did not want to ask for it, children (daughters in particular) still provided some support, most commonly, emotional support. Sons do not provide support very often, and if they do, it is in the form of help with caring tasks that require physical force.

Lucía is her father's only carer, as none of her five siblings participate in the caring arrangement. Though alone, she doesn't want to ask her own children for support. She thinks it's not fair since it's not their role or obligation but hers. Lucía also suffers diabetes and a vision problem. She is now afraid that something could happen to her before her father dies and that she will have no option but to ask her children for help.

> *My father needs constant attention but I cannot tie up my children with that. If some day something happens to me, anything, they will have to care for their grandfather and I don't think that's fair. My eldest daughter is 27 years old, my son 22 years old and Darlin, the youngest, is only 10 years old. I think they are too young to tie up their lives to their grandfather's, because he needs non-stop attention, he needs special foods, help*

> *when taking his bath, he needs everything to be solved for him, and I cannot ask my children to do that, I really hope that nothing will happen to me before my father dies because I don't want to ask them for help. (Lucía)*

Ana María is the main carer of her mother who lives in a nursing home. She visits her mother every other day. She organises her medical appointments and buys her medicines and all she needs (e.g. clothes). Ana María has four daughters and a son, all of whom are married and living with their own nuclear families. Ana María says she would like her daughters to see all the work she puts in caring for her mother. She would appreciate if her daughters would visit their grandmother so she wouldn't have to as often and would have more time for herself. However, she does not receive this support from her daughters, nor she asks for it.

> *It's difficult for me to just say that I am tired and that I need a hand. I could ask my daughters to visit my mother, for example, but I feel weird about that. I could also ask them to take her own children to the residency because my mother loves children, but I can't. I don't want to bother them. They already have a lot to do with their children and their work. (Ana María)*

Ofelia, main carer of her elderly father and with multiple roles says she would never ask her daughter for support, even though she is tired and could use some help. She would never ask her daughter for help, because her daughter's priority is her studies.

In some cases, female daughters provide emotional support to their caregiving mothers. Eugenia provides all the direct care for her elderly mother with high dependency level. She has a weak social network and scarce social support. For her, the only person to whom she talks about her problems and emotions related to their caregiving role is her daughter. Her daughter provides emotional support.

> *When I need to talk to someone to feel less pressure, I talk to my daughter. And she also helps me as much as she can but I know that I can't put this burden on her because it's not fair, because she [the elderly] is my mom. (Eugenia)*

Consuelo, the main carer of both her parents-in-law who live with her, is the only carer who mentions that her children provide strong support in the elderlies' care.

> *You can't imagine how much my children and my husband help. At the beginning I thought that the caring load was too heavy for me! But in reality we all started realizing that between two it was easier, and between three even easier. For example, to take her to the bathroom you have to pick her up between two persons, and then to put her in her wheelchair it is easier among three persons… (Consuelo)*

Consuelo does not question the appropriateness of her children providing support. Her role as main carer is not something that she perceived as her own and sole obligation (as is the case in most other cases in the study). It is not an obligation for her to be the sole carer because she sees she became the main carer rather fortuitously. She is the main carer because she has lived with her parents-in-law for a long time and the physical proximity made her the primary carer when compared to her sisters-in-law. She would like her sisters-in-law and their children to be more involved as she thinks it would make a fairer arrangement. Carers' perceptions on their role and the reasons they have become the carer are important in shaping their experience, as will be examined in Chapter 7.

iii) Partners' support

Partners' support is gender-biased. Husbands or male partners provide financial and sometimes emotional support to carers. They provide direct care to the elderlies sporadically, only when the main carer has to leave the house. In the few cases where men were the main carers, their wives provided support with direct care activities as well as emotional support. Emotional support coming from partners was strongly appreciated by carers.

> *My husband tells me I have to be patient; he calms me when I get angry with my mom… He is like my mother's son, so he understands me. (Sara)*
>
> *Usually my mom does not bother me because she is super quiet, but there are times that I get mad, but my husband is there to tell me to be patient. (María)*

Isabel is her father's main carer. She lives 20 minutes away and visits him daily. Isabel widowed five years ago and found a supportive partner eight months ago. She sees the big difference of a supportive partner compared to being alone. She does not live with her partner, but they see each other often.

> *My partner supports me in everything, he is very important to me in terms of feelings because one cannot be too lonely, that would be a terrible thing. With him I talk and I cry, because there are some days in which I cry, days in which sadness comes down and I can't stop it. (Isabel)*

The presence of a partner does not mean their support can be taken for granted. Social networks, even if it means ties as strong as those between partners are not equivalent to social support (Abel 1991). Some female carers from low and low-middle income households cannot count on their partners for emotional support. Rita, for example, is the main carer of her mother with Alzheimer's disease. She does not receive any kind of support from her husband, her daughter or her son-in-law, all of whom live with her and the elder. She hesitates in asking her husband for emotional support. She claims he wouldn't understand her.

> *I never talk to my husband about my feelings regarding my mom's care. He has his own problems and sometimes men get bored when you start talking about these issues. (Rita)*

Women from low-income households who cared for their parents-in-law also mention they can't count on their partner for support, even if their husbands are the elders' sons and their partners are caring for their own parents. Paz, is the main carer of both her parents-in-law, and cannot count on her husband for emotional support.

> *If I talk about this with my partner and ask him for more help or just time to talk to someone and vent it would be like adding burden to him. I can handle it myself, alone. Also, he already has his own problems. (Paz)*

Victoria is also her mother-in-law's carer. She does not count on her husband for any support other than financial support. Victoria, like Paz and Rita, justifies her partner's lack of support by saying that their partners' already have their own problems. As if caregiving is their own and sole responsibility, even if they carer for their parents-in-law.

> *I cannot count on my husband for consolation or cosiness, because he gets sad. I was once angry and tired and sad, and I cried and everything. He told me 'ok we will leave her in a nursing home'. But that's not the point, because that's not an option, you can't do that, I couldn't do it. (Victoria)*

This supports the finding that, among low and middle-income carers, women expect little from men in the care arrangement, apart from financial support. Ana María, a high-income household carer for her elderly mother notices that her husband does not provide any support other than financial support. She does not justify his lack of support like low and middle-income carers do. She feels uncomfortable with the traditional breadwinner model. Ana María is aware of gender inequality in the provision of care, especially in her generation.

> *I think that to all women, at all times, it has been difficult in some way. I see my daughters today who work like crazy and have to take care of a house and care for their three or four kids. That's tiring for sure. But the biggest difference is that they have husbands who support them and they also split the household and care chores. Us, in my generation, we have husbands who only work. Mauricio (the husband), who is the nicest person in this life, only works. He comes from work, turns on the TV and watches football, and that's it. (Ana María)*

Marita has a nice and supportive husband, but he is not involved at all in elderly care. He spends most of his time at work. He leaves every morning at 7h30 and comes back tired at 8h every night. Marita's husband is 84 years old, she is 79 and her mother is 103. They live together. A paid carer comes Monday to Friday and another one comes Friday to Saturday. Before they started living with her elderly mother, her husband was very supportive with the idea of living with the elderly. He promised her wife that he would stop working so they could spend more time together. However, he changed his mind.

> *He had promised me that he would stop working soon, but one day he went to doctor and his doctor told him that he should never stop working. So, I barely see my husband. (Marita)*

In all, partners (male) generally – but not necessarily – provide emotional support in the form of encouragement and comprehension. There are cases in which female carers do not count on their husbands' emotional support when it comes to caring experiences. Some women carers justify their husbands' lack of support, even if carers were caring for their parents-in-law, but others recognise it as a source of inequality. The relationship between the carer and her partner helps explain the level of partners' involvement and carers' experience with the support (or lack thereof), as will be analysed in the following chapter. Cultural factors, like gender, also explain the support (or lack thereof) received.

The kind of support that carers receive from their partners differs by gender. In cases of male carers, wives' support was varied. Sons caring for elderly parents obtain more material help and emotional support than daughters, and this is also true when it comes to partners' support (Abel 1991). Pedro's wife supports him in many ways. She understands that Pedro is less present and less available to be with her, and that he is exhausted at nights. She also helps him giving by performing some of the direct caring tasks, like bathing Pedro's mother and preparing her food.

> *As I already told you, Mariana (his wife), how can I tell you, she is a queen, that's the least I can say about her, she is a woman who gives unconditional support. She is a good person, a worker, if there would be a grade higher than seven (the maximum mark in Chile's educational system), I would give it to her. She is a support, I never thought that she would be… just perfect in this situation. (Pedro)*

Rodrigo's wife had cancer and passed away a few months before the interview. While alive and in good health, she and Rodrigo's shared his mother's care. She was in charge of her personal care and Rodrigo of the care management (e.g. making appointments with the doctors, taking her to appointments, managing her pension). Now that Rodrigo is a widow he greatly misses the support he received from his wife.

iv) Neighbours' support

Neighbours are key actors in the support low income carers receive. Their participation highlights the absence of other family members in the care arrangement, and the absence of paid carers among these households. Most low-income carers mention the help from people in the neighbourhood when asked about the people who provide support. Neighbours provide sporadic support, usually in the form of surveillance of the elderly if they have to leave the household for errands. On a few instances, neighbours also provided emotional and direct support. Asking neighbours for help was not a habit, but could be counted on.

None of the cases from high middle or high-income households mentioned support from neighbours. When asked specifically about them, they said that they actually barely know their neighbours. This is consistent with evidence of neighbour relationships across the Chilean population. While 12% of people from higher socioeconomic status report knowing the names of seven or more neighbours, 47% of people from lower socioeconomic status do (Encuesta Bicentenario 2013).

> *More than anything, neighbours are there when I have to leave and they keep an eye on my mother-in-law or in case, God forbid, if something happens she knows that she can turn to the lady in front. (Victoria)*

Neighbours are not automatically friends or people a person can count on. Their support requires cultivating relationships, and this was possible for most low-income carers in the study: they have been living in the same house for more than ten years. Silvia, by contrast, recently moved. Silvia only mentioned her neighbour Shirley, whom she has recently met.

> *Now I have a neighbour, Shirley, a petite brunette, she has two kids. Before we were not friends, but after a while, one day, I asked her if she could take a look at my mom because I had to go to the doctor and she offered me to change her diapers! So she helps me, she changes her diapers and gives her a snack. Now I can get out more and relax. She says 'leave, everything will be fine'. She comes here with her children to watch television. (Silvia)*

Mauricio, a low-income carer of his elderly mother and his sister, highlights the importance of neighbours in supporting him. Neighbours are the only source of social support he receives, with the exception of a cousin who visits them once in a while.

> *Many people from the neighbourhood have helped us, economically and emotionally. There is a neighbour who comes to give my sister a bath because she cannot do it alone. There is another neighbour, the girl from the house next door who helps my mom to take a bath, she helps her with personal cleanliness, because my mom does not want me to see her [naked]. Anyways, it's me who washes her hair and my sister helps me in what she can… The girls from the end of the street come to wash my sister, to give her company. Ah! And for the New Year all the neighbours got together, they brought up money, the younger people got together and did it… (Mauricio)*

Mauricio mentioned that he receives his neighbours' support because they, in the past, were also good neighbours, especially when his mother was autonomous and he had more time to spend with them. *"We are harvesting the seeds we sowed,"* he says. Neighbours' support, in this case at least, is based on reciprocity, more than in norms of care or altruism, unlike the support within kin groups (Perren et al 2004).

> *We were transparent, we also helped when we could, when someone asked if we could help we always did, and well now we help if we can… and my mom, although she was a very quiet woman, she helped everyone here, she visited the sick children and elderlies, and all those things. (Mauricio)*

Mauricio also understands his neighbours support is based on reciprocity. He is scared that they will stop supporting him one day because they will get tired of giving, especially now that he and his family cannot give back as much as they receive.

> *They have helped us a lot, a neighbour, for example, sent us a box with food, [with] rice, sugar, and also a box for my mom with clothes for her, and so many things like that, and another pays us the electricity bill once in a while. But I think they will get tired at some moment, because people get tired of giving. (Mauricio)*

For other low-income carers, neighbours were also a source of social support. In general, the support received was more sporadic and not as intense as in the case of Mauricio. There may be a gender component in the social support he receives: male carers tend to receive more support than female carers (Abel 1991) and so was the case in this study with social support coming from relatives and co-workers to male carers, irrespective of the economic situation of the carer.

6.8 Geographical distance and cohabitation

When independent living is no longer possible for an elderly, the older person may move into an adult child's home or the adult child can move to the elder's house. In other cases, cohabitation precedes dependency as the adult child and elderly have been living together before the onset of need. Cohabitation is one of the most common forms of intergenerational solidarity; it reduces the costs of housing and food and facilitates the provision of direct support to relatives with special needs. Cohabitation is driven by both the need for elderly care and the lack of support for it (Hakkert and Guzman 2004).

Cohabitation could be experienced as a positive or difficult situation by carers. Research shows mixed results. Cohabitation is appreciated as carers are more available and do not have to over-adjust their routine to provide care (Call et al 1995), it allows for a more reciprocal relationship among mothers with dependency and their daughters (Dwyer et al 1994) and is linked to a lower prevalence of depressive feelings (Montoro 1999). Despite these positive findings, cohabiting with the elderly in need of care negatively interferes in the relationship between the carers and their family (Walker et al 1995), can increases the perceived burden of care and lead to a lower satisfaction with care by those who receive it (Dwyer et al 1994). When carer cohabits with the elderly in need of care, more time is dedicated to caring and a greater variety of care tasks are done (Bittman et al 2004, Fast et al 2004). The inability to escape caregiving responsibilities weighs on carers who live with their care receivers (Joel and Martin 1998). When the carer's household is shared by the carer's spouse, their own children and the elderly in need of care, the caregiver had poorer mental health, reported more symptoms of depression, restless, and feelings of isolation as effects of care (Brody 2004).

In Chile, the majority of elderlies in need of care cohabit. Some 85% of elderlies live with someone else, and this percentage increases with the elderly's dependency level (SENAMA 2009b). Official statistics cannot distinguish between the elderly who cohabit with their main carer and those who cohabit with someone else, but it is highly likely that most cohabiting elderly carers share the home with their main carer, especially among lower income households and elderlies with high dependency level.

In Chile, elderlies' residence configuration in the last stage of life does not respond to the search for better living conditions after retirement. It is associated with a loss of individual autonomy and the reliance on family support (Amador and Brenes 2006). In this study, cohabitation is a solution to reduce costs and to simplify a carer's everyday life by avoiding the need to commute and its temporal and monetary costs. Most carers in the sample adopted cohabitation as a response to moderate or high dependency (except in cases where carers and the elderly have lived together from before the onset of dependency).

Carers' experience with cohabitation in this research was not unequivocally a resource or a constraint. The value of cohabitation depends, to a large extent, on the relationships that emerge. They, in turn, depend on carers' biographies and the history of relationships, as will be developed further in Chapter 7.

6.8.1 The different paths to cohabitation

In the study, 31 carers (over a total of 42) cohabit with the elderly. The path to cohabitation is sometimes gradual; in others it is a continuation of longstanding cohabitation. In 19 cases, carers and their parents or parents-in-law had been living together for a long time and well before the onset of the elders' need for care. As the elderly begin to need help in daily life activities, they stay in their home, continuing the cohabitation. The cohabiting daughter or son becomes the main carer.

This is the case of Consuelo. She married 30 years ago, and her parents-in-law offered them to live with them until they had the money to afford independent life. A few years later, Consuelo's children were born and they had the money to live independently. However, grandparents and grandchildren had gotten used to this conviviality and didn't want to be apart. Consuelo and her husband decided to stay. Three years ago, her mother-in-law had a cardiovascular accident that made her completely dependent. Her father-in-law became moderately dependent. Consuelo became their main carer.

Pedro's story is similar. He, his wife and daughter have always lived with his parents. They share the property, with a five-meter corridor separating Pedro's house from his parents'. When his mother had a stroke and lost most of her autonomy, Pedro became her main carer.

Fátima shows the gradual nature of cohabitation. She got married 18 years ago and moved out of Santiago to live in the north. When she had children, her mother usually travelled to her daughters' house to visit her and help her caring the children. When Fátima moved back to Santiago, her mother was used to staying with her, so the tradition that Fátima's mother spends a night or two at Fátima's place was maintained even though the mother had her own house in Santiago. As years passed and Fátima's mother began needing help, she stayed more often in Fátima's place, until one day, they decided that she should live definitely with them. Fátima's mother, now 85 years old, agreed.

Other carers, from lower income households who were born and raised outside Santiago came to the capital city looking for employment opportunities. As labour migrants, when they settled, they had their parents join them. Such is Lucy's and Bernardita's case. Sandra left Panguipulli, in the south of the country, and came to Santiago at the age of 18 looking for employment. Her mother stayed in the south until she became dependent and Sandra brought her to live with her and her three daughters.

For Pilar, cohabitation became a part-time arrangement that has been satisfactory so far. She takes turns with her sister; she spends the night at her father's place every other day. Her father lives in the house next door. Pilar spends the day at her father's place providing care. This arrangement allows the elderly parent to have company all the time and the two sisters to have time to rest from caregiving tasks by alternating nights.

6.8.2 Cohabitation can become a constraint

Cohabitation is not always the easiest and preferable solution. Eliminating the physical distance between the carers and the elder can become a potential constraint. Trinidad lived with her husband when her mother started needing everyday help. Her mother lived with two of her sons and a daughter-in-law but it was Trinidad, being the female sibling available, who became the main carer. For the first months Trinidad commuted daily to her mother's place (30 minutes by bus). She then decided to move-in and live with her mother to avoid the commute and be available for her mother day and night. Trinidad's husband stayed alone at their place. This care arrangement lasted for four years, until Trinidad realised that she needed her own space. A doctor had found her depressed and suggested she take some distance from her caregiving role. Trinidad also needed to be closer to her husband who was also getting older and needed company and more help in daily life activities.

Cohabitation can be complicated because it brings about a change of family dynamics and infrastructure in the carers' house. The nuclear family has to adapt to a new situation, sometimes eroding their relationships. Carmen lives with her mother ever since she started needing care. Her mother has severe physical and cognitive dependency. Carmen has two sisters that visit daily and help her with caregiving tasks and give Carmen emotional support. Carmen stopped her work as a cleaning lady when her mother moved in. To receive some earnings, she began caring for her two grandchildren while her daughter worked. One of her sisters also cares for her three grandchildren, and brings them daily when visiting Carmen's mother. Cohabitation brought a major change in Carmen's nuclear family life. At home, there is now her mother, her sisters and the grandchildren. Carmen values her sister's presence and support, and values the fact of spending with her mother her final years. However, she sometimes feels the pressure of the cohabitation situation when her husband says he feels invaded with the house full of people all the time.

For María's family, the cohabitation situation is complicated in terms of physical space. For three months now, her 98-year-old mother lives with them. They are four (María, her husband, her daughter and her son) plus María's mother. They live in a small house and as there is no space in the house, her mother sleeps in the living-room sofa (not a convertible sofa, just a sofa). María's children complain they are not allowed to make noise or watch television in the living room after 22h, the time their grandmother is sleeping. María prefers the physical space constraints to the time and monetary costs of commuting to her mother's house. She is not worried about her son's or her daughter's complaints. For her, as they do not help out with the elderly care they don't have the right to complain. Despite the dissatisfaction with the space constraints they have a fairly good relationship.

Some carers who live with their dependent parents mention feeling absorbed by their caring tasks and by the relationship with the elderly. As developed in Chapter 7, living with the elderly parent in need of care could be felt as a pressure if the relationship with the elder or siblings is somehow deteriorated. Fátima, Sara and Bernardita feel consumed by their elderly parent in need of care. These carers carry out most of the caring tasks by themselves and receive little support from their social networks. They do not delegate care with external carers, making it difficult to have respite from caring duties and from the strained relationship with their parents or parents-in-law.

> *She [her mother] is very attached to me. My mom [she exhales] absorbs me very, very much, and she wants to know everything, everything, why did I do this or that, she wants me to stay with her, and even further, she wants me to go to bed at the same time she goes to bed! So then that makes me angry, but then I realise I do not have to be that way… (Sara)*

Cohabitation can simplify the care arrangement reducing the costs associated to commuting. It is sometimes the only care arrangement possible. Eliminating the distance implies a re-adaptation of family dynamics and spaces, and the carer could become completely absorbed by elderly care. Importantly, how carers experience cohabitation will depend on the relationships it creates among family members and between the elderly and the main carer. Chapter 7 will develop how relationships relate to carers' experience and how situations can become resources or constraints.

6.9 Conclusions

This chapter described the context of the care experience and the different social and economic situations where it takes place. It highlighted sources of potential constraints. The spectrum of carers' situations is large. Difficult economic conditions, advanced age, multiple caring demands, combining care work and paid employment, the level of dependency of the elderly, the existence of formal and social support and cohabitation, are all situations that can become constraints or resources for carers. Depending on the situation, carers are subject to stronger or weaker constraints, and some of those constraints are more objective than others. A bad financial situation is an objective constraint; it is a situation that unequivocally becomes a difficulty and puts pressure on the caregiving experience. By contrast, cohabitation – like most other situations discussed in this chapter – can be a constraint for some carers and a resource for others. Similar situations are not experienced in the same way by different carers. For example, multiple caring demands are experienced as a constraint by some carers but as a source of respite for others. Having a paid job, the existence of formal support or cohabiting with the elderly in need of care are also situations that are experienced differently by carers.

Although these situations explain a part of carers' experience, they do not fully explain the intensity of carers' daily experience. The following chapter delves into the emotions of carers, coming from their relationships, carers' biographies, perceptions and expectations towards their role, allowing for a more comprehensive understanding of their experience.

Chapter 7. Understanding the intensity of the care experience through the weight of emotions

Silvia is 52 years old. She became her 84-year-old mother's primary and only caregiver five years ago. Today, her mother has severe cognitive and physical dependency. Silvia lives with her partner and her mother. Silvia has no children. They are a low middle-income household; they own their house; it is small and well cared, with a small and nice garden. Silvia worked as a nanny before being a carer; she hasn't worked for pay since. Cohabitation started when her mother's health deteriorated five years ago. It was a solution to meet her mother's care needs by being close to her. Cohabitation allowed Silvia to reduce the financial expenses associated to maintaining two households and commuting. Silvia's partner completely agreed to cohabitation. She has a sister who does not participate in her mother's care.

When Silvia refers to her partner she does so with affection and gratitude, but recognises they are "*more like a pair of friends than a couple of lovers.*" As a result of her mother's care, Silvia is very tired, she does not have the energy to chat or have sex. At night, she puts her head on the pillow and immediately falls asleep. She hasn't taken vacations in years, and her routine is identical throughout the seven days of the week. A neighbour helps her with her mother's care when Silvia has to go out to do some errands or buy bread. A doctor or a nurse from the primary health centre comes to do a check-up and exams to her mother once in a while. Apart from this sporadic support, she doesn't receive any social support; Silvia provides direct and emotional care and organises doctor appointments, in addition to the housework.

Silvia's health has also deteriorated. She is undergoing medical exams to discover her ailment. Doctors think she might have breast cancer, but they are waiting the results of the biopsy for confirmation. Silvia's major concern now is not to die before her mother.

As it stands, Silvia's experience as carer has many constraints and one can be led to believe she experiences it with a high feeling of pressure. However, although difficult and tiring, Silvia appreciates the opportunity of caring her mother. Silvia loves her mother and she is grateful of how her mother was with her throughout her life.

> *I honestly find that I'm not overwhelmed even though I am tired and I do nothing for myself, my priorities are my mom, my mom, my partner, my mom and then, maybe, me. Because my dear mommy will leave me someday, the moment when she will leave will arrive, then I will never see her again (in tears). (Silvia)*

What makes Silvia's caregiving experience one of fulfilment and not one of pressure? The intensity of 24/7 care for continuous five years, the economic constraints, the almost complete lack of social support, absence of social life and her deteriorated health would not predict her being satisfied with being her mother's carer. Understanding the experience of care requires going deeper into relationships, motivations and biographies to finally consider how emotions weigh in the experience of care.

Indeed, carers' satisfaction becomes clear when understanding they past relationship with the elderly, the motivations and reasons to provide care, their own past life and the way they perceive their sibling's absence, their neighbour's support and their husband's company.

Violeta has a similar set of situations – perhaps even more favourable situations – to Silvia, but experiences her mother's caregiving differently. Violeta is 62 years old and lives with her 86-year-old mother who has had a cognitive dependency for five years now. She has cohabited with her mother for these five years. They live in a modest and beautiful house, with plenty of natural light, a well-cared garden and six pets (two dogs, a turtle, one cat and a pair of birds in a cage). Violeta is an only child; she is married, she has a married son and a grandchild. She comes from a medium-income household and she considers her financial situation as "*a good enough situation that allows for living without financial worries*." She retired from work five years ago, after having worked for 40 years as a secretary in a government agency. She has a good marriage though they are now like friends because she puts most of her energy caring for her mother. She has a good relationship with her son and his wife. She loves her granddaughter and she sees her once a week. She doesn't have time to see friends but she takes part in a weekly knitting club (meetings are at her house) where she gets to meet nice people. A doctor in the primary health care centre sees her mother often. Violeta trusts the doctor.

When compared to other carers in this study, Violeta has relatively low levels of constraints in her life. Though she does not receive support from relatives, she has no financial constraints, receives respite, has a good relationship with her husband and has some social activities beyond caregiving. However, being her mother's carer is a very difficult experience for her. She experiences strong pressures on an everyday basis. She recognises her situation is supposed to be a good one due to the lack of constraints and favourable situations, but she still finds caring for her mother extremely difficult.

> *I cannot accept my situation [of being my mother's carer], I cannot accept the obligations, I have never liked obligations, except when working. Having to get up early to attend her, having schedules for everything: her medicine, her meals... It's hard, and I know I should be grateful because as compared to other people my situation is good. What happens is that I have things of the past, rages, memories, it is clear that she was not a perfect mother, maybe I am not either, but with my son I have a good relationship, he cares about me and I care about him, so it is a different story, we have had a very different relationship when compared to the one I had with my mom. (Violeta)*

Putting Silvia's and Violeta's experience side-by-side shows that similar situations are experienced in different way by carers. Caring in favourable situations can be experienced with high intensity, situations with many constraints can, nonetheless, be experienced with low intensity.

There are elements in Silvia's and Violeta's stories that relate to the relations involved in caregiving and the perceptions they have towards their role as carers and their potential satisfaction or dissatisfaction with their role. These elements include the relationships with the elderly, the different reasons and motivations for caring, and different ideas of what appropriate care is. These variables explain the difference in Silvia and Violeta's every day caring experience.

Indeed, if the care experience is often described as painful or binding, it can also be experienced positively (Caradec 2009), including in situations marked by strong levels of constraints. Understanding the everyday feeling of pressure experienced by carers requires taking into account a range of subjective variables (Le Bihan et al 2014). The first two chapters on the experiences of care (Chapter 5 and Chapter 6) argue that carers' situation must necessarily be placed in a more general context. This chapter argues, more specifically, that this context must take into account the carers' emotions, dictated by their personal life story and the relationships involved in care. They will, depending on the situation, strengthen or otherwise alleviate the intensity of their experience (Campéon and Le Bihan 2013). This chapter reviews the emotional dimension of care, complementing Silvia and Violeta's cases with others to unravel the complex phenomenon of the experience of caregiving for an elderly parent or parent-in-law in need of care.

In understanding caregivers' experience through their emotions, the focus is on the importance individuals accord to their own situation (of their support network, their family and working life, of their social, emotional and economic context, and more generally yet, their life). This situation and the consequent potential constraints in carers's situations explain part – but not the entirety – of the difficulties experienced by carers. Caregivers' experience cannot be reduced to the set of tasks, situations or constraints but must consider the emotional dimension of caregiving.

Care is tinged with emotional elements and normative valuations. Emotions are configured through the history and relations of carers (Garcia 2010). Carers' emotions towards the caring situation are rooted in a historical relationship with the elderly in need of care, the degree of investment in caring activities, the desire to be present for the elderly and the difficulties to delegate tasks. They must be all analysed taking into account the life history to understand the perception and feelings that the carer has towards her or his role as carer (Le Bihan and Mallon 2013).

The act of caregiving grows out of socio/emotional relationships. It creates, in turn, complex human relations (Himmelweit 1995). Care for a dependent family member has a social and emotional component, and results in complex emotions which can be sometimes positive, sometimes negative or, very often, mixed (Bazo and Domínguez-Alcón 1996).

A previous chapter showed that care is a complex notion that can be considered along two dimensions: care as work and care as affection. Care refers to the activities of caregiving (a work) but refers, also, to a relationship marked by affection. Care refers to love and also to labour. To care means looking over the material needs of another person, and caring may also mean that the carer feels special concern for another person. Care as love, affection, concern and a personal relationship with another being is 'caring about'. Care as work is 'caring for' (Leira 1994). Understood in this duality, caring is not a heavy load or a joyful activity per se. The experience of care depends on the relationship between carer and care receiver, the conditions under which care is given and whose choice it is (Kremer 2007).

Chapter 5 showed how care encompasses a diversity of practical activities; care is, without doubt, work. Chapter 6 showedthat care takes place in a broader context. This chapter explores the emotional dimension of care and shows it is crucial to understand how carers experience care. In particular, four emotional elements contribute to better understanding carers' experience: i) the reasons for becoming a carer for an elderly parent or parent-in-law and how carers interpret them ii) the relationship carers have with the elderly and other family members; iii) the biography of carers; and iv) the ideals of what appropriate care is.

7.1 Reasons for becoming a carer: motivations and social obligations

Caregiving for the elderly in need is a mosaic of the distinct and complex interpersonal experiences people involved go through (Gubrium 1991). Individuals structure their values by acting and interacting. Care practices mobilise all kinds of moral considerations about what is right or wrong, what should or should not be done. Individuals, therefore, act according to a series of *reasons*. These reasons are not only rational but especially relational and develop in context (Kremer 2007). The assumption that individuals are autonomous in their decisions related to the elderly care is not correct (Finch and Mason 1993). No matter which elements are behind the investment of a person in the elderly care of a parent or parent-in-law, caregivers' reasons for caring frame their experience and are key to understand how they experience their role. The decisions that led to elderly care are not only governed by rational evaluations of the situation, but involve powerful feelings (love, guilt, jealousy, tenderness, etc.), linked to family positions, and rooted in long stories (Le Bihan and Mallon 2017).

This section explains the origins of the investment of carers in their role. It shows that the nature of the decision, obligations, motivation or reasons to become a carer of an elderly parent or parent-in-law in need of care has consequences in carers' emotions and in the way they experience their daily life (García 2010).

Among the most important motivations to provide care to an elderly relative are the emotional ties and the obligations arising from family ties (Kahana and Young 1990), which explains why in many cases family carers are dissatisfied with their role but nonetheless maintain it (García 2010). Several motivations and social obligations identified in this study explain why a person becomes the carer of an elderly parent or parent-in-law in need of care. Motivations observed among family carers found in the study include: 1) the motivation to pay back to an elderly parent for what he or she did in the past (*delayed reciprocity*); 2) the motivation to repair the elderly's past life and allowing him/her live in better conditions during the final years of life (*sense of mission, delayed reciprocity*); 3) a strategy by the part of carers to invest in their own future, expecting their own children will follow the example and care for them when needed (*preparatory reciprocity, role model*). While motivations can be felt as voluntary, obligations are not. In the study, several carers adopt the role: 4) because no one else is available to care for the elderly; or 5) because social and cultural norms dictate that it is the right thing to do (e.g. women are expected to be carers before men). In certain cases, there is no specific reason or moment in which the role is adopted. Other circumstances, rather, explain how carers adopt the role, as is the case when there is cohabitation between a child –potential carer – and the elderly before the latter become dependent. Sometimes, the motivation or obligation to care is preceded by an explicit preference by the part of the elderly to be cared for by one of his or her children.

One does not become a carer by chance or from one day to another. This role appears as a combination and interplay of different motivations and obligations. They are very often an implicit process in the eyes of the carer and the rest of the family (Campéon et al 2012).

In many cases of the study, the reasons why carers adopt the role are a combination of these motivations and obligations. Often, the social obligations underlie the reasons and the apparently voluntary motivations for becoming a carer. For example, the motivation to pay back an elderly father may be backed by norms dictating that daughters or sons have the obligation to reciprocate to an elderly parent. Or if a carer decides to become the carer for the elderly mother carer because no one else in the phratry is available, then cultural and social norms might dictate that she or he will have to become the carer and not another sibling, an obligation underlies the motivation.

All these types of decisions and situations that make a carer adopt the role, and the way carers feel about these decisions and situations have important consequences for their experience. For example, family carers who are motivated to provide care by a sense of duty, guilt, or social and cultural norms are more likely to resent their role and feel more pressure than carers with more positive motivations (Pyke and Bengston 1996). Also, if the decision is taken collectively, there are is a higher likelihood that the carer will receive support from other relatives to care for the elderly, reducing the constraints and potential sources of pressure. However, it could also be that a collective decision generates pressure in the carer. Carers may feel frustrated over the loss of their freedom, if they were not the protagonists of a decision that determines their daily life and wellbeing (García 2010).

7.1.1 'Paying back' to elderly parents

One of the motivations underlying the decision to assume the role of carer is to pay back to the elderly parent. Caring for her mother results from a decision Silvia made and has resulted in a daily life not free from potential constraints (e.g. lack of financial means, severely dependent mother, lack of support, and Silvia's own deteriorated health condition). Her main motivation is to give back for what her mother did for her in the past.

> *She gave me life, this is like 'giving a hand back', I always tell her 'I change your diapers and clean you, as you also did for me'. She was a good mother (in tears). (Silvia)*

If her partner hadn't agreed to have Silvia's mother come and live with them so that she could be cared for, Silvia would have moved out to care for her mother.

Caring for an elderly parent in need can be seen as a way to return the care a parent provided to them when they were children (Durant and Ollie 2006). 'Paying back' to an elderly parent, or *delayed reciprocity,* provides a moral imperative for children to care for parents in need (Clarke 2001). It is a form of generalised reciprocity, based on moral norms that give meaning to what a family should be and, in many cases, are linked to religious beliefs. Unlike other social groups, members of a family do not expect immediate exchanges in response to the provision of care (Starrels et al 1997). The satisfaction of carers towards the care experience is not affected by the ability or inability of the elderly to give back in the present or near future (Dwyer et al 1994, Finch and Mason 1993). Family relationships can be conceived as a long history of mutual exchanges, some more balanced than others, in which the distribution of support varies over time. The care relationship motivated by delayed reciprocity is a way of returning past support (Call et al 1999). As in Silvia's case, when care is rendered as retribution, a feeling of gratification is derived (Durant and Ollie 2006).

However, care motivated by retribution means that becoming a main carer is a response to feelings of emotional responsibility for the wellbeing of the elderly. This emotional component could lead to caregiving to be experienced as demanding, as the feeling of responsibility tends to be boundless (Le Bihan et al 2013).

Josefina is the main carer of both her severely dependent parents because she wants to return the support they offered her in the past. This motivation is felt as a binding obligation and felt with pressure, much in contrast to Silvia who feels she decided freely. Josefina comes from a high-income family and the elderlies' pensions cover all the care-related expenses. She receives strong support from her siblings and has support from external paid carers. Her parents have needed constant help for five years; five years that seem *"eternal and difficult"* for Josefina, who has postponed her own interests, her time with her grandchildren, and has to see her elderly parents deteriorating (especially hard for her is to see how her mother, who has an advanced Alzheimer's, mistreats her father after having been a good couple). Despite these difficulties, she does not question her role as carer because she has to return what they gave to her and to the rest of the family in the past. She feels the obligation and finds it impossible to ignore the obligation, even though she feels the pressure of her situation.

> *I am the main carer of my parents because we had exceptional parents, they were responsible, caring parents, and we got in life an amount of affection and care so large that I would not have the stomach to leave this couple, who did everything for us, alone. But I understand very well, very, very well, that people who have outstanding accounts with their parents at this stage in life they abandon them. We have exactly the opposite experience, we had a dad who always cared for us, even when we were grownups, they loved us with boundless affection, with 100% commitment to us and to their grandchildren, the love this couple have for their grandchildren and children is huge. So there is clearly a 'giving back' to them at this stage in life. This is the reason why my commitment to them is not questioned. (Josefina)*

7.1.2 To repair the past life of the elderly

Some carers want to offer the elderly in need the opportunity to live the last years of life in better material or emotional conditions. In this study, this was often seen among individuals coming from low- or middle-income families who had experienced upward social mobility. These are carers who live in better conditions than their parents and parents who've had a difficult life (e.g. marked by strong financial constraints or suffering)

For these carers, the decision to take on the role as carer is driven by the desire to ease their parents' end of life (Martin and Le Bihan 2006). Carers view their role as a *mission* to make the elderlies' last years as good as possible at whatever price, independent of the investment required (Le Bihan and Martin 2008, 2006). This mission provides meaning and value and reduces carers' feeling of pressure, no matter the difficulties they may face in their daily life (e.g. economic constraints, lack of social support).

Sandra is 42-year-old, she grew up in a rural area in the south of Chile. Her mother widowed at young age with 11 young children under her care. Sandra assumed the role of carer without regret, without pressure, and driven by the motivation to give her mother a pleasant end for her life after all she had suffered. Sandra came to Santiago at age 18. She was the last among the phratry to leave her mother who stayed in the south until she became dependent. Sandra took her to live with her and her three daughters (Sandra is a single mother). Sandra has a relatively good relationship with her siblings who help with caring tasks sporadically and give her money if extra costs arise, but it is Sandra who carries the responsibility for all her mother's care, her house and her three daughters.

> *My mom had a very sacrificed life, she widowed very young with eleven children under her care, the eldest was 15 years old when it happened. When my father died, people said my mother went crazy for a while, but then she healed. She worked long hours to give us bread everyday (crying). I couldn't allow them to take her to a nursing home, so that's why I give everything for her (keeps crying). I left everything for her. I never got out of my house again, I preferred to be completely dedicated to her, without any interest, because her monthly pension is only 90 thousand pesos [approximately 130 euros], in other words, there is no economic interest, none. The only fact is seeing her caring for us [the siblings] all by herself, the fact that she never got married again… so you think about all that and a huge impulse to give her a better life arises. I will be with her until God takes her away. (Sandra)*

Mauricio is the main carer for both his dependent elderly mother and dependent sister. He is the only man in this nuclear family. The three have always lived together. He has never questioned his role; he says he will never give up his role because his mother has had a very difficult life. As in Sandra's case, Mauricio would like to give his mother a pleasant end to her life. Though in Mauricio's case no one else was available to take on the role as carer, he does not mention the unavailability of others as a reason to provide care; he still finds it a personal option to give his mother a good end-to-life. Repairing his mother's life gives Mauricio a sense of accomplishment; he would never put his mother in a nursing home even though it would allow him to find paid employment and reduce his financial constraint. Financial constraints are the most difficult part of his role as carer, but his motivation for reparation rather than delegating the care task to a nursing home compensates for any constraint. A driver in this sense for reparation is the fact that Mauricio perceives his life as a very satisfying one (he had paid employment and was financially independent, he partied, travelled around the country, etc.).

> *My mom had a very sacrificed life, her dad died when she was 11 and then after three years her mother died, we are talking about 1932, imagine, she was only 11 years old. Her brother staid with her and treated her as an employee, he did not give her food, my mother often went hungry and cold, and I think that's why she always feels cold now. Her brother did not send her to school, my mother had to take care of his children, they beat her, she was her brother's and sister-in-law's maid. And then she married a man who they say it's my dad, but he was horrible to her too, he was always drunk, also misbehaved with her, beat her, abused her, came home drunk with friends, my mom had to get up at three am to serve them, to give them food. Give her a better life; make her*

> *happy, that's the only thing I want. I know she is going to leave (die) soon, that's the law of life. (Mauricio)*

Sandra and Mauricio, and also Silvia, come from low- or low-middle-income households. Reciprocity, in the form of reparation for Sandra and Mauricio, or paying back for Silvia, was never mentioned a sense of obligation or a negative force for them to take on the carer role; it was, rather, a motivation to adopt their decision and a source of accomplishment. It is possible, however, that the obligation was internalised and therefore not conscious. In this sense, this *delayed reciprocity* provides a moral imperative for elderly care (Clarke 2001), but one that is not necessarily experienced negatively.

The same sort of motivation to provide care was experienced negatively by Josefina, who comes from a high-income family. Josefina was the only case that framed this reciprocity in the context of an obligation. As a result, she is more inclined to experience care with a greater feeling of pressure.

It may be that for Silvia, Mauricio and Sandra the norm for reciprocity was internalised to the point they don't even notice it. Even though the norm exists in all cases, not all of them sense it. For those who are aware of the norm the pressure is stronger, as we see in Josefina's case. It could also be that that there is a higher ethic of care in those coming from lower income families, that the collective was stronger than the individual in providing meaning to care.

7.1.3 Investment in carers' own future

Some carers have the expectation that once they become an elderly their children will care for them by following their own example. They find in this expectation the motivation to care for the elderly in the present. This motivation is sustained as a form of *preparatory reciprocity* (Hsu and Shyu 2003) or as being a *role model* for their children (Gupta and Chaudhuri 2008). This motivation reduces carers' sources of pressure, even in situations of constraint.

Elisa is motivated to care as a form of safeguarding against her own future care. Coming from a high-income household, she lives with her seven school-age children, her husband and, for one year now, her 87-year-old mother-in-law who needs care on a constant basis. Two women live in the house as well, providing support for household tasks and some of the elderly direct care. Her husband is an only child and she always knew that her mother-in-law would end living with them.

> *Since I met him, since I liked him I knew that if this [the relationship with her husband] went forward, it will come with a father and a mother-in-law with it, there is nothing new. (Elisa)*

Though being her mother-in-law's main carer it is not a surprise – and perhaps an obligation – for Elisa, she accepted the role because she would like to spend the final periods of her life surrounded by her children and under their care. She does not want *"to be left somewhere alone."* The best way to convey this personal desire to her children is by setting the example herself. Historically, she has had a good relationship with her mother-in-law, which facilitated the acceptance of her role and experiencing it with a lower feeling of pressure (the relevance of relationships in determining the feeling of pressure is discussed in more detail later).

> *I wouldn't like to be left somewhere alone, and that my children say ok, we leave her alone, we have nothing else to do… I think that for my kids, the fact that they have seen me caring for their grandmother will change their perception towards the elderly and they will be more responsible with their own parents' care in the future (Elisa).*

This motivation is not common, however. A considerable amount of carers in this study, especially those experiencing their role with pressure, would not like their own children to care for them when they are old and in need. They do not want their children to have the same constraints and pressure they experience.

The contrast between Elisa and the majority of other carers makes it clear that Elisa's motivation to provide care is not independent. It is partly the result of a good care experience (explained by a good relationship with her mother-in-law, with her husband, and children, and the match between her ideals of what appropriate care is and her mother-in-law's current care arrangement). The motivation towards investment reinforces the reduction in the intensity of the experience.

7.1.4 Social norms create a sense of obligation

Family care is, most of the time, considered a voluntary decision. Though the moral pressure to provide care can be rather strong, even when there is no legal duty to do so (Meulen and Wright 2010). Reciprocity is a process that helps understand why and how people become committed in helping relatives, but it does not tell the whole story (Abel 1991, Finch and Mason 1993).

Not all carers assume the role *to pay back* the elderly parent or *repair their past life* because they think the elderly deserves it. In some cases, carers do not even feel that their parents were good parents in the past, quite the opposite. Yet these carers who find no motivation in reciprocity do not abandon their elderly parents. They became carers because of a strong sense of obligation, because there is a social norm dictating that it is the right thing to do.

> *This is a decision I made because I want and because of my [moral] conscience. I could be working or doing something else, but I chose this [to be her father's carer]. But I am very tired. I cry a lot, but I have to be strong until my dad will be gone, for now this is my task. It is a responsibility I took, and there is my conscience telling me that I have to keep going, keep going no matter what. (Isabel)*

Care comprises a set of moral principles that offers a way of thinking about what is necessary for human wellbeing, flourishing and survival (Tronto 1993). The normative nature of care is not solely of relevance to the assessment of social policies (Sevenhuijsen 2003), normative questions are important in our everyday lives both because of our dependence on others and because we care about things and people (Sayer 2011).

Some carers who adopt the role by obligation to norms are aware of such moral obligation. For others, the obligation is internalised in such a way that carers do not question their role. The awareness of the obligation increased the likelihood that carers are unhappy with their role, increasing the likelihood of experience care as a negative experience, or one with a strong feeling of pressure. A caring relationship always involves emotions; in the context of care as an obligation there may be an absence of positive feelings or feelings of love. Given the relational dimension of care, emotions will always be part of caring (Le Bihan and Mallon, 2017).

> *It's that I am the youngest [that she became the carer], I was a girl and all my siblings were married when my mother widowed, I was 13 years old, then we were both together, my mom and I, always both together. When I got married, I thought [for the first time] 'oops this backpack is mine' (she laughs looking worried), and there is also love in between and attachment, so I said to my husband before marrying him 'ok I will marry you but I will take my mother with me because she is part of me'. (Fátima)*

The norm that a child, a woman, the youngest, the eldest or the unemployed adult children should care for a parent is present in all carers lives, whether conscious or unconscious.

The norm of solidarity which drives the obligation to care does not impose itself on everyone in the same way. To understand its origin it is necessary to go beyond the study of individual motivations and into the intra-family negotiations and strategies, and to address the construction of normative belief and social prescriptions (Martin and Le Bihan 2014). A normative hierarchy of obligations puts certain actors at the forefront of this obligation, indicating the existence of a normative system built not only in familiar and intergenerational relations but also at the societal level (Walker 1993).

Familial and intergenerational dynamics explain why a certain child among the phratry becomes the carer. The decision – or obligation – to become a carer is usually not an individual decision, but a relational process within the family (Roberto 1999). Many relatives forego care, waiting for others – in their eyes normatively better suited to care – to be left with the obligation to care (García 2010). It is usually the woman, the single, the non-employed who assumes the role not out of motivation but out of the obligation that stems from social norms dictating they are the most suitable to care.

Being a woman, a decisive determinant to become a carer

Tradition, deeply embedded notions of a woman's social worth and the value of her work, and the distribution of power within a society contribute to explain why caregiving tasks fall disproportionately on women (WHO 2001). Gender is a decisive factor determining whether a person becomes a carer of an elderly parent or parent-in-law. The belief that women are the natural providers of care is extended (Bazo 1998, Ungerson 1987); women are expected to have a natural instinct for this type of work (Bazo and Ancizu 2004). The effect of the internalisation of the role of gender is reflected in the different motivations to provide care (Bazo 1998) and in the fact that most women find their role as fair and satisfactory (Walker et al 1995). For women, care is crucial. It is not only an activity, it shapes their identity (Kremer 2007). In Chile, for 86% of the elderly cared for by family members, it is a woman who provides care (most commonly daughters, then wives). In this study's sample, 39 carers are women, three are men.

Women accept that being a carer is the right thing to do. Their role is accepted either because it's seen as a natural thing to do and/or because the more economically dependent a person is, the less exit possibilities she has, the less voice (Kremer 2007). Carers' role is determined – although not exclusively – by the gendered norms (Finch and Mason 1993) and the gendered moral rationalities (Duncan and Edwards 1999) which confirm the fact that becoming a caregiver is linked to the gender identity (Kremer 2007). Often, it is the same women who bring up gender bias with their discourses, pointing to the supposed inability of men to adopt caregiving roles, giving them less responsibility when distributing care work among family members.

Elisa, like Victoria, Cintia and Consuelo, is the main carer of an elderly parent-in-law in need of care. It is not their husbands who take on that role, it is them because they are women and their husbands are men. They don't expect it to be any other way.

Adela, Sara, Colomba and Francisca are the only women in their phratry and care for their respective parents because they are women. They don't question the fact that it is them who are the main carers; this role corresponds to them as they are women. They don't blame their brothers for not being the main carers, but in some cases they would like more involved by the part of their brothers (e.g. Francisca).

When there are other women in the phratry, carers interpret sister's lack of involvement as something very unjust, as if care was solely the role of women and should be shared. This feeling is not directed to men in the phratry. Fátima, Eugenia, Trinidad, Silvia and Lucy do not want to see their sisters. They despise them because they are not as involved as they are in the elderly care. They don't want their sisters to provide sporadic support. They want to share elderly care in equal parts, because they are all women. These female carers with sisters feel that all women have the social obligation to provide care to the elderly parent in need. This unfairness contributes to them experiencing their role as carers with pressure.

Among this study's female carers, 24 have brothers. These male siblings are excluded from the possibility of becoming carers because they are men. This does not cause any dissatisfaction to the actual women carers. Their gender is a sufficient and valid reason to become a carer. As seen in other studies, being male is considered a legitimate reason for not providing care (Finch and Mason 1993, Walker et al 1995), while being a woman is by norm a reason to be eligible to care for the elderly parent in need.

A man becomes a carer when there is no other option available in the family (Horowitz 1985). This is the case of the three and only male carers in the study. Rodrigo is an only child. He is a widow and when his wife was alive she was the main carer of Rodrigo's mother. He took the role as there are no women in the family, no sisters and no wife. Mauricio has a sister with physical dependency. His mother used to care for his sister until she also started needing help. Mauricio, who has always lived with his sister and mother took on caring for his mother and sister when his elderly mother was no longer able to provide care and actually needed it. Pedro has two sisters, a wife and a daughter. He has always lived with his parents. When his mother had a stroke and developed a dementia, Pedro took on the role as her main carer because of his physical proximity with his mother. The siblings decided not to move the elderly mother out of her place. Pedro, as all the men cases of the study, receives a strong support, in his case from his sisters and wife and from an external paid carer.

The gender-biased social norm towards care is most evident in women carers' annoyance when there are other female members in the phratry. This annoyance is stronger when the relationship between the carer and the elderly is already strained; the annoyance also worsens the relationship with the elderly in some cases, even though the carer and the elder had a good relationship in the past. Fátima is 46 years old, she lives with her husband, their three children and her elderly mother for whom she cares. Fátima is the youngest of five siblings. She has three sisters and a brother. She lives in constant indignation because she finds it unfair that none of her sisters taking on the role of carer of their mother in an active or regular way. She would like to take turns with her sisters to care for her mother. She would like to be able to take vacations with her nuclear family while one of her sisters cares for the elderly mother or even have a part-time job as her sisters do. Fátima does not accept that they don't take on the role of carers. They are all women, she says, they all have a nuclear family and they all, as human beings, need to do things in life other than elderly care. Fátima's does not mention her brother, her anger is directed towards her sisters, not her brother.

> *It is unfair. I know she is my mother, and I love her very much, but it's unfair. My husband has a good financial situation and we would like to take vacations, but we can't. I would like to have a paid job but I can't. I can't because I have my mom. And I find that unfair, I argue and fight. Now, for example, I would love to take vacations but my sisters have all their vacations already planned and they said to me they can't stay with my mother. My husband is a professor so we can't take vacations whenever we*

> *want but only in February, but my sisters already planned their vacations in February (with an expression of anguish and anger on her face). (Fátima)*

When compared to men, women are more likely to be out of the labour market or, if employed, more likely to receive lower earnings. Women are, as a result, often in a situation of economic dependence and disadvantage in the brokering process of the caring decision. This disadvantage is often exploited, implicitly or explicitly, by other relatives in distributing or assigning caring responsibilities. Men's financial independence grants them higher power in the family, which crystallizes in their greater freedom to avoid caring responsibilities (García 2010). And the more women are responsible for house chores and care, the more difficulties they have in finding a good, well-paid job that eliminates the economic dependence (Kremer 2007).

Being the available one, and the conditions necessary to exclude others from the care arrangement

Not all daughters provide equal amounts of care for their aging parents. Just as men might be non-participants, or collaborators in caregiving for their parents, women in the phratry exhibit different levels of participation (Willyard et al 2008). Many siblings do not assume a fair share of the caregiving tasks, and instead, one sibling typically provides more care than the others (Pillemer and Suitor 1996). When a sibling cannot be counted on in the elderly care arrangement *dissociation* occurs, and dissociation is more common among brothers but also occurs with sisters (Matthews and Rosner 1988). More-involved siblings may experience frustration and anger toward those who are less involved in caregiving (Strawbridge and Wallhagen 1991). This variability is, at least in part, explained by variation among family members in their feelings toward intergenerational support and family members (Gans and Silverstein 2006). Besides the individual feelings and motivations, the individual circumstances within the family also count.

Frequently, the main carer becomes one because others (usually siblings) were unable or unwilling to provide care. These carers (usually daughters) accept their role as inevitable and or appropriate (Brody et al 1995).

Among women in the family availability for care is usually directed towards an unmarried daughter, daughters who are not employed, and daughters or daughters-in-law who live with the elderly or in close proximity. They are more likely to become carers of elderly parents (Connell 2003). If none of these women exist within a phratry, then a man is more likely to provide family care to an elderly parent, at least among the sample of this study.

In this study, many carers recognised that they care for the elderly and receive little support because no one else is available. The degree of the acceptance of siblings' unavailability will determine part of the carers' feelings towards their role and the relationship with the siblings. Some experience this obligation to care negatively. Others believe that the rest of the phratry has legitimate excuses for not being carers so the actual carers, although feeling obliged to care because that’s the right thing to do, don’t put blame on their siblings. When carers accept the reasons for siblings not to participate it is not a source of conflict within the phratry. Perceived legitimacy in others’ lack of participation leads to less conflict and lower intensity experienced by carers.

The lack of support from siblings can be legitimised on the basis of gender (men are more likely to be legitimately dissociated than women), employment (the employed more likely than the non-employed), other care responsibilities (those caring for children or other elderly more likely than those without other care responsibilities), financial situation (those in a precarious financial state more likely than those with a good situation), health (the sick more likely than the healthy), marital status (the married more likely than the single) or cohabitation (those cohabiting with the elderly more likely than those not cohabiting). The legitimacy of the excuse for not providing care, does not depend on the excuse directly, but on the set of circumstances and relationships under which these excuses are mobilised (Finch and Mason 1993). It is in this sense, then, that the absence of consensus over legitimacy for a family member’s excuse within a phratry can lead to family conflict.

In this study, the most important situations and conditions that made a carer available and exclude siblings are i) being single or ii) being out of the labour market.

i) Marital status: single

Within the women in the phratry, the one who is single is more likely to become a main carer. Causality, however, is not clear. On the one hand, a single daughter may assume that role or, on the other, as they slowly became engaged in care their free time and social life diminishes little by little, reducing their possibilities to find a partner. In this study, single carers who adopted the role had lived in the same house with the elderly.

As single women, they stayed in their parents’ house. As the elderly’s needs increased this daughter began dedicating more time to care and her possibilities to meet people and potential partners were reduced. In this context, single carers say they are the main carers because they are the only among the sisters who was not married or didn’t have a partner. These single carers feel the situation is unfair when they have had fewer chances of finding a partner and forming a family as a result of caregiving, which acts as a source of pressure. This is increasingly the case when single carers compare their situation to that of their sisters who have a family.

Bernardita is the main carer of her elderly father. They live together. Bernardita has two sisters and two brothers; their mother died 15 years ago. Elderly care lies completely on Bernardita, her sisters visit them sporadically, one of the two brothers and both sisters help with money if extra costs with the elderly care arise (e.g. hospitalisations). In explaining how she became her father's carer, Bernardita says it's because she is the only single among her sisters. All sisters used to live together, but when her sisters married they moved out. Ten years ago, her father had stomach cancer. At that time Bernardita was already the only woman in the house. She realized that she was going to be alone in the future as her sisters were married. Bernardita decided not to get married to dedicate herself to caring for her father. Bernardita works as a cleaning lady and adapts her work schedule depending on her father's health.

> *I chose not to marry; if I had married maybe my dad would not have been with me. I actually thought about all of that, between sending him to a nursing home, which I do not like because they are either extremely expensive or of horrible quality, or staying with him and being single forever. I prefer to stay with him and I have no regrets. (Bernardita)*

Although she feels that being single and fully dedicated to her father's care was an explicit decision, she also feels it was an obligation that fell upon her, given that none of her sisters was available, and that she felt her father couldn't be left alone.

> *It is difficult, I have never been able to have a partner, I never married because there is my dad... Sometimes I think that everything is so unfair. I could have had my family, my children, my own house. And then I think, well, maybe if I had a husband we wouldn't be like this, I know it wouldn't be the same with my dad, and that makes me very sad, the fact that he might have ended up alone. But, yes, there are moments when I feel sad and lonely and I would love to talk to someone else other than my dad. (Bernardita)*

ii) Working status: out of the labour market

Among the women in the phratry, those who are out of the labour force when the elderly's dependency path begins are more likely to become caregivers. Non-working women amongst working sisters report their non-working status as a reason for which the obligation to care fell upon them. It is a reason why working sisters refuse to take on the care obligation. Main carers in this situation find it unfair. Like with single women, being out of the labour force and becoming a carer reinforces itself: women who become carers will forego the chance to find paid work.

Sandra has ten siblings: five sisters and five brothers. She argues she is not able to share any caring responsibilities with any of her siblings because they are all in paid employment. Other carers might find this situation unfair, but Sandra is strongly motivated to provide her mother's care because she wants to give her a better life in her last years. She finds it legitimate that her sisters don't participate because they are all in paid employment. Sandra adopts her role with satisfaction in spite of the many constraints she faces. The circumstance of why the obligation fell on her and not her sisters (because she was out of the labour market) and her constraints – which could lead to a high feeling of pressure – is offset by her motivation to provide care in determining her feelings towards her care experience.

> *Well, I am the carer of my mom because all my siblings are working, and as I was in the house I took on the role, but they come to visit once in a while during the weekends, and I have one sister that works sporadically and she comes more often, whenever she can. But it has been a sacrifice, but I do it with much love because she is my mom. (Sandra)*

Fátima, by contrast, has three sisters and a brother. Their mother's care load relies exclusively on her. For Fátima, the fact that her sisters are all working and do not have time is not a valid excuse for not participating in the care arrangement. Fátima would like to have a job as well, but her role as main carer eliminates that possibility. The contrast between her situation and her sisters' and the perceived illegitimacy of their excuse for not participating makes her upset and angry with her sisters. She experiences her daily life as carer with pressure as a result.

The way carers see their siblings' lack of engagement in the elderly care and experience that, is related to their own level of *individualism* and *collectivism* (Pyke and Bengston 1996). Sandra and Fátima exemplify this. *Individualistic* carers emphasize autonomy, self-fulfilment and personal achievement. For them, as for Fátima, satisfaction with their role in the elderly care arrangement depends on it being voluntary and egalitarian. *Collectivist*-oriented carers like Sandra are more likely to feel that family obligations that provides a sense of continuity, belonging and identity, meets their emotional needs. This explains, at least in part, why siblings' lack of support is lived with pressure by Fátima and why Sandra experiences caring for her mother's something that fills her with satisfaction, although none of her ten siblings participate in the elderly care.

It is possible that collectivist-oriented carers tend to come from the lower socioeconomic status, because the level of individualism increases with the rungs of the social ladder since more options are available for individuals with more economic means. In countries where the State has adopted a stronger role in the providing welfare, for example, belonging to different generations is associated with different levels of individualism-collectivism. In these countries, individuals from younger generations, those who have access to more opportunities, tend to be more individualistic (Guberman et al 2012). In Chile, however, political context and the government's role is far from that of welfare states in developed countries, the gradient of individualism-collectivism is determined mostly along socioeconomic lines, and less so along generational lines.

7.1.5 Religion and spiritual fulfilment as the obligation and motivation to provide care

Religious beliefs are connected to the motivations to provide care among family carers of elders in need of care (Guberman, Maheu and Maille 1992) and, as previously seen, they could also be source of emotional support for carers, especially during the more difficult times of the caregiving path, when they lack of hope or lose patience.

Religious beliefs dictate the obligation to provide care. Religion dictates the norm that it is mandatory to provide care and carers bound by these beliefs cannot escape the strong normative obligation to care for the elderly relative in need. The accompanying spiritual fulfilment provides the motivation to maintain the caring role. Once the caring role is assumed, religion provides emotional support to carers experiencing strong pressure in their daily life. It motivates them to keep with their role, no matter the cost. Blanca and Antonia experience their daily life as carers with high intensity. For them, religion is one of the most important reasons why they provide care, it also allows them to withstand difficult situations and a high feeling of pressure.

Blanca is 78 years old and the eldest of a phratry of nine. She has two daughers, four grandchildren. She is the main carer of her 102-year-old mother; she lives alone with her mother. Her mother has required assistance for 24 years and has been severely dependent for three. Only one brother helps her with her mother's surveillance one Monday a month. This allows Blanca to go to the supermarket, to the primary health centre and pharmacy to get medicines and to the municipality to get her and her mother's pension. Blanca then comes back to give her mother food and medicines and to change her diapers. Blanca's brother does not provide direct care to her mother.

Blanca is tired and sick herself with arthrosis and chronic back pain. She faces financial constraints and feels lonely. Although she struggles with her caring role, she feels the strong moral obligation to provide care. This obligation stems from her religion beliefs. The obligation is strong enough that she would never give up her role.

> *I am a prisoner, I am a prisoner! I can't get out of the house, only to pay the bills and do errands once a week… I am sick too, I have back pain and as I my fingers are all crooked. My back, my toes as well, they are all crooked. Being my mom's carer makes me very sick, but it's a moral obligation. It's love for a mother and it's a spiritual devotion because I am Catholic. (Blanca)*

The belief in God is one of the reasons for caring. As in Antonia and Blanca's case, faith in God is also a reason to carry on with caring duties despite difficulties of the situation and the negative emotions towards care.

Rita is the main carer of her cognitively dependent mother and also an only child. She expresses how important her faith is, especially when she is tired and need strength.

> *My faith in God, when I want to climb alone to the top of a mountain alone and have no one to care for or just get in bed and sleep without having to worry about anything, it's in those moments when my faith in God gives me the strength to keep going. (Rita)*

Paz mentions how tired and lonely she feels in her daily life as carer of her parents-in-law. She also says that it is only God that gives her strength to carry on.

> *I don't talk to anyone when I am feeling sad, I mean, I talk only to God. To him I give my burden. I tell him: 'God help me so tomorrow can be a better day'. (Paz)*

Antonia's mother has cognitive dependency. Her father died thirty years ago; her sister twenty years ago. Antonia is her mother's main carer. They live together as they have always; they are a middle-income household. Her mother's mental health began deteriorating five years ago and her level of dependency is now high. Antonia recognizes that only her faith in God and her religious beliefs keep her by her mother's side, caring for her. She struggles, she feels overwhelmed. She gets angry and has rage issues from past unsolved issues with her mother. Antonia regrets her life, but she keeps going as her mother's carer because she feels the moral obligation to do it. She provides care and continues despite the feeling of pressure not because she wants to pay her mother back, and it's not that she wants her own children to follow her example and care for her (she doesn't have any children). Religion provides her the norms of how to behave as a daughter, which is to provide care. Religion also provides the moral support to keep going.

> *I am distressed with my mother's care and in the end I think that my only support is faith. I go to mass, I tell the priest, I tell him what happens to me and he tells me I better not think too much about it, that I should accept and leave it to God and live day by day. This is, like, what makes be the best [person]. I learned it in church classes and in the mass, we are told to offer. Look, my eye is shivering, it's because I am talking about things that hurt me… I sometimes try to be a good Christian, Jesus endured so much pain for us and we do not want to live in pain, but we must accept pain as part of life. The Bible says it in many parts. When my mother could still do her things alone I went took a course in the church to become a missionary, and it [being a missionary] was something precious, to just go to other people's house to spread God's good word. It helped me to remain standing, not to think about my situation and problems all the time. (Antonia)*

Antonia's case shows that religion's role in shaping the caregiving experience and reducing the intensity goes beyond facilitating a better relationship between the family carer and the elderly, as argued in previous research (Chang et al 1998). Although Antonia admits having a high level of religiosity helps her coping with her role, the relationship with her mother is not good. For Antonia, religion provides the obligation and the support, it does not mediate her relationship with her mother.

7.1.6 Conclusions

Family carers become such because of several life situations and norms. They are motivated to care for several reasons. Those who are motivated by a sense of duty, guilt, or social and cultural norms – by a sense of obligation – are more likely to resent their role and feel more pressure than carers with more positive or voluntary motivations. This finding is observed in other studies (e.g. Pyke and Bengston 1996). When the excuses other family members have for not participating in the elderly care are perceive by the carer as legitimate, carers are less likely to perceive their role in a negative way. For them, pressure will not come from their family members' dissociation.

Motivations help explain why caregivers in certain situations experience care differently. However, the motivation to provide care does not always relate to an intense experience. The decision to take on the role as carer to repair for an elderly past life can increase the feeling of pressure for some carers by increasing the standards of what care should be, but can also be a source of gratification and be pleasant for others in the form of delayed reciprocity.

The normative component behind the caring role is strong in this study. Carers who are more individualistic-oriented and have clear personal desires that differ from elderly care will experience these norms with greater pressure, as these norms hinder and postpone their own desires. Collectivist-oriented carers find satisfaction and fulfilment in following social norms that dictate that elderly care is the right thing to do. The relative absence of cases individualistic-oriented cases in the study, contrasts with research from developed countries, where carers' motivations to provide care are often rooted in individualistic motives. In developed countries, individualistic motives are driven by the desire that each family member remains autonomous from the priorities of affection and love. In an individualistic scheme, delegating caregiving tasks is the rule (Camaille and Martin 1998, Le Bihan and Martin 2008, Single 2000). In the context of developed countries and a more generous offer of public support for the elderly care, more individualistic oriented elderly carers won't necessarily see their own desires obstructed by their role as caregiver.

Motivations, like caregiving situations, cannot remain isolated from variables that also affect the carers' experience of pressure. A crucial such variable is caregivers' own biography and individual interests as well as their relationship with sibling and the elder in need of care.

7.2 Relationships, the key to understanding the care experience

Relations are key to understand carers' experience. Care is work, but one that is inherently relational. It does not exist in a vacuum; it is embedded in intimate personal relationships, it is embedded in social relationships (Abel 1991). Caregiving experiences cannot be interpreted without consideration to the relationships embedded in care. It is from relationships that most emotions will arise, and without considering the emotional dimension of care, we cannot fully understand the experience.

More broadly, the quality of people's lives depends on the quality of the social relations in which they live, and on how people treat one another (Sayer 2011). A positive relationship between the carer and both siblings and the elder in need is important to the carer's experience. Care is commonly the product of an intensification of a pre-existing relation pattern (Walker and Pratt 1991) and the intensity of the care experience is rooted in a historical relationship with the elderly in need of care (Le Bihan and Mallon 2013). Exchanges in the family build the moral commitment to care in situations of dependency. Situating the historical relationship between family members allows to better understand family carers' investment and their daily experience (Campéon et al 2012).

Despite their importance and the acknowledgement by some authors that care is a relationship (e.g. England 2005; Glenn 2000; Leira 1994; Tronto 2012), an in-depth analyses of the ways in which relationships facilitate or undermine caregiving and carer's experiences are lacking (for a review, see Bastawrous 2011). This section shows that the relations carers hold with their social environment are key to understanding the way they experience their daily life as carers. As highlighted in the introduction to this chapter, relationships can make a very difficult caring situation to be experienced with positive emotions (e.g. Silvia). Relationships that give rise to conflict can make a comfortable care situation become one felt with strong pressure (e.g. Violeta). Several relationships are important to understand caregivers' experience: the relationship with the elderly, with siblings and siblings-in-law, and with the carers' own nuclear family. These are discussed separately in the following sections.

7.2.1 The relationship between the carer and the elderly

Upon the onset of the dependency path, both the carer and the elder in need have to redefine their previous roles to fit the new relationship. The redefinition is of special intensity for a carer of an elder with mental or cognitive deterioration. In these cases, family members often struggle with ambivalent feelings about whether to reformulate the previous relationship or redefine the relationship in terms of care (Rolland 1999).

The provision of care for an elderly parent or parent-in-law is situated in a long relational history between the child (or child-in-law) and the parent (or parent-in-law). The provision of care by children is unique in that the nature of their relationship with a parent was, at one time, a period of dependence on the parent who, for much of the child's life, would have been viewed as an authority figure who provided nurturing and resources. Upon assuming the caregiving role, however, the adult child becomes the support provider as the parent becomes dependent on the child for assistance. This may result in a shift in the relationship and a reversal in roles, which highlights the importance of exploring both the current and past parent-to-child relationship (Bastawrous 2011).

Considering a life-course perspective places the focus on the history of the relationship to understand care. It acknowledges that family members lead interrelated lives, resulting in interdependent development and roles that people assume are constructed over time (Marks et al 2008). Understanding caring from a historical perspective implies that the pre-caregiving relationship may have important implications for how the caregiving relationship develops. For example, adult children who recall being rejected or poorly supported by their parents in childhood are less involved in their parents' care in later life (Whitbeck et al 1994). Also, high-quality relationships tend to be associated with better wellbeing for children performing caregiving roles (Bastawrous 2011).

Relationships are not exclusively "good" or "bad". In every relationship there are, simultaneously, both positive and negative elements. The balance between the positives and negatives is different in different families and among different elderly and carer relationships (Abel 1991). This overall balance is what determines the quality of relationships and, in the case of caregivers, help configure their caring experience.

This section reviews the main aspects determining the relationship between the carer and the elderly. These aspects, along with other components of the caring experience (tasks, context), determine the intensity of the caring experience. The relational aspects include: i) maintaining a positive past relationship with the elderly, ii) reviving old conflicts, iii) care as an opportunity to create a new relationship with the elderly, iv) role reversal, v) aggression to the elderly in need of care, and vi) caregivers absorbed by the care relation.

Maintaining a positive past relationship with the elderly

A positive relationship with the elderly in the past is intrinsically related to the way caregiver experience their role. The closer and better quality the past relationship between the elderly and the carer, the more caregiving will be assumed as an individual decision and less as a imposed decision by the family or an obligation (García 2010) which, as seen above, relate to carers experience of pressure.

In this study, cases reporting a positive past relationship tend to find it less difficult to live their role. However, a second group of cases with a positive past relationship make carers feel sad and frustrated due to the difficulty of maintaining such a positive relationship in the context of mental health deterioration or the conflicts and tensions that arise from daily life, which is most clearly seen in cases where the main carer cohabitates with the elderly in need of care.

Pilar is one of this first group of carers. She has always had a good relationship with her elderly father in need of care, as well as with the rest of her family. She does not experience care with pressure. Her father has a physical dependency and his mental health is intact. She has one brother and one sister and they all live in the same street. Her experience is marked by her historical good relationship, which she has been able to maintain.

> *I always grew up with my parents' affection and we have constantly been united. I thank God we never fought either for inheritance or for things such as that one has more and*

> *the other less, on the contrary, we have always supported each other, when one is weak the others are there supporting him. (Pilar)*

Care is mostly under Pilar's responsibility with a strong support from her sister; they take turns in spending the night with her father who lives in the house next door, Pilar's her brother supports with money. Pilar spends the day at her father's house providing care. When she needs to go out, her sister provides support. She attributes her adopting the role of main carer to always having a good relationship with his father and to the fact that she has always been caring for other family members. The good relationship between Pilar and her father has been, in fact, better than her sister's. Although she recognises that caring for her father has its difficulties (e.g. restricting her free time), she doesn't feel pressured or overwhelmed. For Pilar, care routines and caring tasks are experienced gently.

> *I always got along really well with my dad, it's that I have a good character, my sister has another character, she is very impulsive, so that's why I do most of the care, because I realised that as my sister didn't get along very well with him she has little patience, sometimes when she stays with him she calls me upset, she called me because she loses her patience. That usually happens when my dad's diapers need to be changed, my sister really can't stand that, she doesn't tolerate the strong smell. For me, care for my dad is much easier, we have always had a good relationship and we keep it that way today. (Pilar)*

Elisa is a married woman from a high-income household. Her husband is a single child and she always knew that one day she would have to care for her mother-in-law. The excellent relationship they have had and that they have been able to maintain facilitates Elisa's acceptance of her role and experiencing the role it with a lower feeling of pressure.

> *We have a great relationship and that dates from when I met my husband. At some point, as most people get good to fight, my father-in-law, when he was alive, he sometimes called me by the phone saying that he could not say anything to his wife, so what he was asking me was to talk to her because she [Elisa's mother-in-law] listens to me. (Elisa)*

Elisa recalls that when she was dating her husband, her mother-in-law was very motivated by their relationship. Her mother-in-law took her side when Elisa and her now-husband had minor disputes in front of her.

Silvia has always been close to her mother. They met every Saturday and some weekdays when possible. Silvia remembers her mother as always being available and willing to help and listen. Silvia has a strong positive affection to the mother. The elderly also had a good relationship with Silvia's partner, whom she considered as her own son. Today Silvia's mother is in bed and hardly recognises her. However, the good relationship they had in the past makes Silvia care for her mother with love and patience, no matter how tired or difficult a day can be. \

A second group of cases, with a positive past relationship with the elderly, find it hard. Rita cares for her mother with Alzheimer's. It is hard for her to maintain a relationship with her mother like she did before the onset of her mother's cognitive dependency. The contrast between the positive relationship she had with her mother and her current relationship is emotionally very painful. Alzheimer's has completely changed her mother's personality and Rita has had to get to know, understand and love a new person. It's not an easy task, the memories of the good relationship they have in the past strains her new relationship, and the comparison between both relationships upsets Rita.

At times, daily-life interactions escalate to conflict. The everyday care routine and closeness with the elderly person can erode relationships that were positive in the past. The everyday difficulties and fatigue can make the carer upset about some details of the elderly behaviour that had they not been involved in the care relation they would have passed without bothering them. The strain of everyday care and its capacity to erode good past relationships is especially true for carers who cohabit with the elderly parent in need of care. It is not exclusive to elderly with cognitive deterioration. Such is Fátima's and her mother's relationship.

> *Uh (she exhales), she freaks me out sometimes. She asks me everything, she asks me for example things like: 'can I take a yoghurt?' Why does she have to ask that if we have been living together for many years now?! (Fátima)*

Cases from this study show that the dynamic of the relationships with the elderly depends on the carers' filial relationship to the elderly. All women caring for an elderly parent-in-law, have had good relationships in the past with the elderly they care and maintain the quality of that relationship. This is even the case when the carers' husband is the only child and carers adopt the caring role as an obligation in the absence of a daughter to take it, suggesting that caring was not a choice. By contrast, daughters and sons who care for their parents in need all tended to have a more intense relationship with the elderly they care for. This intensity makes the relationship more vulnerable to potential conflicts. It is possible, however, that in this study there is less variability among daughters-in-law because only six were interviewed (compared to the 36 cases of daughters or sons). Other studies have found that the relationship between adult women and their mothers is perhaps the most complex and emotionally charged of all relationship within the family (Cohler and Grunebaum 1981).

The difference between the relationships daughters-in-law have with the elderly and that of sons and especially daughters with their parent in need of care can be explained by the longer history of son's or daughter's relationship with the elderly when compared to that of a daughter-in-law and a parent-in-law. Another explanation is rooted in the fact that individuals hold different expectations towards a parent than towards a parent-in-law. Since individuals tend to hold more expectations on parents when compared to parents-in-law, expectations towards parents are more likely to remain unfulfilled and may therefore affect the current relationship.

In summary, having had a relatively good relationship with the elderly parent in the past is related to the way a caregiver experiences their role. For some of them, a positive past relationship makes it easier to maintain a good relation upon the onset of dependency and the shift in the roles within the relationship. These carers experience their role with less pressure. For others, a positive past relationship is a source of pressure if the carer finds it difficult to maintain the same relationship with the elderly because of the new condition of dependency. In this study's cases, those caring for an elderly parent–in-law tend to remember their past relationship with the elderly as a collection of good memories, when compared to daughters and sons who have more variability in their past relationship with the elderly opening more possibilities for an intense experience to arise as a result of negative elements in their relationship.

Reviving old conflicts

Antonia's house is full of things. She keeps objects everywhere. Things that she finds on the street. Things that she gets from neighbours. Things that she has bought. She doesn't use them; she never gets rid of them. She keeps them, wherever they fit. Her accumulation of things parallels the bad feelings she has accumulated due to the historically bad relation with her mother.

Antonia is single and the only child of her 98-year-old mother. They were a family of four in the past, but both her sister and her father passed away more than 20 years ago. Antonia used to work as a dressmaker but had to quit when her mother began needing daily help. She receives no help for her mother's care. Antonia thinks her sisters got married to rebel, leave the house and escape from her mother. Antonia couldn't. Her personality was weaker, she was more of an introvert and shy.

Antonia's experiences as something unbearable. She feels overwhelmed, depressed and isolated. She has always had a bad relationship with her mother. Her childhood memories of her mother are negative. Her mother was very authoritarian, she was not nice to Antonia and was not available when Antonia needed her. Although Antonia tries to forgive her mother because she had, herself a difficult childhood and adult life, Antonia cannot break away from all the anger she has accumulated. She would like to run away, but her moral obligation keeps her caring for her mother. She sleeps long hours; she cries a large part of the time she is awake and watches television to disconnect. The historically bad relationship with her mother limits any possibility of her care experience to become pleasing.

> *I got angry and kept quiet. I never told her anything, but that was not good for me. She got mad and said horrible things to me, and that made me mad and I accumulated that anger. I never told anyone my pain because I didn't have anyone to talk to. I was ashamed to tell people that I have a bad relationship with my mother. The few times I told a friend about the problems with my mother my friend told me 'ah but you shouldn't worry about it, it's your mom and she is old'. So I thought no one understood me, no one lived what I lived, and the few friends I have told me that I should handle it by myself. So I never again share my pains and worries. (Antonia)*

She remembers her mother as a very protective mother. When Antonia was a girl, her mother wouldn't allow her to leave out of the house to play with neighbours. When Antonia was an adult, her mother always asked where she was going. Whenever Antonia went to church, her mother said that she should better take her bed and sleep there. Antonia now regrets being so lonely and isolated. She blames her mother for it. Antonia's case is in line with other research that finds that custodial and combative relationships between a mother and a daughter in the past, are related to higher carer pressure (Ward-Griffin et al 2007) and that carers who expressed anxiety concerning their past relationship with their parent experienced more pressure (Grand et al 1999).

The fact that Antonia's mother has Alzheimer's disease complicates their relationship even more. It makes it difficult for her to re-establish a new relationship with her mother to overcome their past difficulties.

Violeta's experiences care similarly to Antonia's. She experiences care for her mother as difficult and full of pressure even though her situation does not seem very difficult. She has a supportive husband, a married son and a granddaughter whom she sees often. She participates weekly in a knitting club and lives in a municipality that provides a wide variety of services for the elderly and retired people. But her difficult past relationship with her mother weighs heavily, making her experiences care intensely and with difficulty.

> *You know what? Care is sad when there is no affection… My childhood was very sad and restricted. My mom came to Santiago to work as a nanny for an Italian family. My mother came from the North [of the country]. I do not know if she got pregnant here or there. She has never told me anything, I don't know what my real last name is; in the end I am an XX. I cannot heal from my past. It hurts me a lot. Yeah, well sometimes I'm not nice to her, but it is that I have had problems with her for years. Look, I do not know who my dad is… now that I am 66 years old I'm still questioning it, I want to get that out of my head. When I was a girl I always told my mother to get out of the house where we lived [in the house of the Italian family from whom she worked] and have our own place, but she never agreed, and I ended up leaving when I was 17 years old. I just left my mom and left to live on my own… You know, the heaviest part of it all for me is when I am bathing her. That's when I snap, I get hysterical, it's like all my anger arrives at that time. I hate seeing her, like, so puny, and then I find her so manipulative, maybe she can do many things alone and she is lying to me again, at her 86 years of*

> *age…I have always had zero relationship with my mom. Before she lived here I visited her once a month to bring her pension and her groceries and that's it. (Violeta)*

Antonia and Violeta experience their elderly mother's care with strong intensity, marked by their past conflicts with the elderly. They are both their mother's only child and, from their perspective, they have no other option but to care for their mothers. From their point of view, a mother must be cared by her children, no matter how much they are loved or appreciated, how good or bad the relationship is. This moral obligation to provide care adds an additional source of pressure to their bad relationship, making their experience even more difficult.

Care as an opportunity to re-create the relationship with the elderly

Not all carers who had bad relationships with the elderly parent in the past maintain that negative relationship once they become carers. In some cases, becoming a carer is an opportunity to reconstruct a broken relationship or an inexistent relationship. For these carers, reconstructing the past relationship helps them deal with the difficulties of their care situation.

The entrance hall to Adela's apartment has unpacked grocery bags. She didn't have the time to put the groceries away when she came back from work. All windows are open. On the day of the interview, her mother had taken off her diapers and defecated throughout the apartment. Adela dropped everything to clean up quickly before the smell became stronger. The male carer that looks after her mother when Adela is at work does not provide intimate care. He didn't know what to do when she took off her diapers and decided to just leave the elderly woman for Adela to take care of the situation when she came back. Adela arrived, exhausted after shopping for groceries, a full work day and a one-and-a-half-hour commute. Though grocery bags were still in the entrance hall, Adela was able to manage the chaos before the interview. She looks tired. Her mother is clean and in her pyjamas.

For five years now, Adela is the main carer of her mother with Alzheimer's disease. Adela has four brothers but none help with care. Adela works full time and during the day a male neighbour cares for her mother under a paid arrangement. She fears this man will quit because her mother's dependency is increasing and the man does not provide intimate care. Adela thinks she might need to quit her job, but she wouldn't like to. Adela took the decision to be her mother's carer because she knew no one else would do it and, as she emphasises, "*she is my mother*". Adela has a partner and they live apart. Her only son lives in the south of Chile. She visits him once a year and takes her mother with her when visiting him. Adela would like her brothers to help her at least one week a year so she can take vacations with her partner. For the five years she has been the carer, she has only gone for vacation to places where she can take her mother.

Adela is tired. She feels constrained in the things she can do because of the care arrangement. Before her mother's dementia, Adela and her mother had a difficult relationship. Her mother lived close to the beach, two hours from Santiago. Adela barely visited her. Her mother had a difficult character and Adela lacked the patience to be close to her. Adela appreciates, however, the opportunity to be her mother's carer and reconstruct their relationship. With Alzheimer's her mother has a completely different personality than she had when her mother was not dependent. For Adela, caring is an opportunity to get along with her mother and become closer after a long history of distance. Dealing with her mother now that she has changed her personality is not a difficult task. The way Adela perceives this new relationship and the process in creating it has helped her to experience her mother's care with a sense of fulfilment and satisfaction, despite the difficulties she faces.

Dealing with a parent with a cognitive deterioration, such as one due to Alzheimer's disease, is not always a positive opportunity for the relationship, as discussed earlier. Dealing with a parent's changed personality can be a matter of sadness and pressure. Rita used to have an excellent relationship with her mother. She is an only child and she always lived with her mother. They continued to live together when Rita got married and when Rita's daughter was born as well. Her daughter's partner has now joined them. Rita's relationship with her mother has always been positive. For Rita, her mother was a source of unconditional support; her mother has always been a friend. When her mother developed Alzheimer's, Rita had to learn how relate to an unknown person.

> *We had a very good relationship. That's what I miss the most (she cries). My mother was my friend, and now she is gone. I mean, her body is here, but she is a different person, she is not the mother I had, the one that listened to me if I had a problem, the one that always gave me her comfort and support. I miss her. Now everything is different. That's the hardest for me, accepting that she is no longer here. (Rita)*

Pedro's feelings are very similar to Rita's. He also dislikes the new relation he has with his elderly parent in need of care. His mother is totally different from the one he knew. He misses his mother as she was before she had a stroke and the dementia she developed. Pedro's mother had a pivotal role in the family. She was a strong woman with a high emotional intelligence. It makes Pedro sad not being able to maintain the relationship he had with her.

Pedro's situation has, by far, fewer constraints than those of many other carers in the study. He has a strong social support coming from his wife, daughter and his two sisters. He has a fairly good economic situation that allows him to pay an external carer whom he trusts. He has a job and a supportive boss and colleagues. However, he experiences his role with a strong feeling of pressure. This feeling of pressure cannot be attributed to his situation, but from the fact that their relationship has changed. He can no longer talk to her mother the way he used to. He can no longer count on her. The relationship they had is now a painful souvenir.

> *Seeing my mom like this is terrible. She was so happy and so active; she was always talking with neighbours, smiling. She was the oak of the family. And now she is someone else, and that makes me suffer, to see her like this, I cannot accept it yet, it's too hard. (Pedro)*

The difference between the past and present relationship between the elderly parent in need of care and the carer can be a source of pressure or an opportunity to heal past relationships and, therefore, a source of satisfaction. This relational pressure or opportunity is more important in explaining carers experience than the difficulties or constraints posed by caregivers' situation. The resulting relationship is crucial to understand carer's experience.

Role reversal

Care provision by children is unique in that the nature of their relationship with the elderly parent was, at one time, a period of dependence. For much of the child's life the parent would have been viewed as an authority figure who provided nurturing, support and resources. Upon taking up the caregiving role, however, the child becomes the provider of support. This may result in a shift in the relationship and a reversal in roles, which highlights the importance of exploring both these facets in the context of the perceived parent-to-child relationship trajectory (Bastawrous 2011).

In this study, some carers explicitly mentioned that their relationship with the elderly has experienced a role reversal. They now feel like a parent caring for the elderly as a dependent child. In many cases, this new relationship has helped carers to cope with their situations and allowed them to make the experience more acceptable. However, in other cases, carers feel uncomfortable in seeing and treating the elderly as a child.

Some scholars are critical of the perception of role reversal in the relationship between the adult child and elderly parent. Abel (1991) claims that role reversal in the caring relationship breaks a cardinal principle of gerontology in that the elderly should not be considered children and despite any disabilities they should be accorded all the rights and privileges of other adults in our societies. Brody (2004) states that a person does not and cannot become the child of the adult child although their roles are enacted differently in late life. Seltzer (1990) says that role reversal is an inadequate and inaccurate approach to understanding the relationship, and it is also conceptually, ideologically and therapeutically limiting.

Notwithstanding these critiques, a large part of the cases in this study considered that their relationship with the elderly parent is reversed. In Chile, the general population's image of the elderly is that they are not autonomous and depend on other people. Elderlies feel they are not treated as they should and deserve to be treated, and that the experience and wisdom that they accumulated over the years are underused and not valued by the various actors in society (SENAMA 2015). It is no coincidence that 73% of the Chilean population declare that people aged 60 years or older are unable to look after themselves, while only one in every four people in that age group have some degree of dependency (SENAMA 2009b).

Florencia feels her mother is her child. This is evidenced in her home's decor. Her elderly mother spends her day in the living room, which is decorated with toys and stuffed animals that Florencia has bought for her mother. Florencia is single and her mother a widow; Florencia's father died eight years ago, which coincides with her mother's health deterioration. Florencia and her mother have always lived together and have had a good relationship in the past; she is an only child and the only one who provides care for her mother. Today, Florencia does not recognise her mother in the elderly women she cares for. Alzheimer's disease has changed her personality and makes her very dependent on Florencia. Her mother spent a few months in nursing home a year ago, but the bad caring conditions in the nursing home made Florencia take the decision to bring her back home. In bringing her mother home, Florencia lost her job as a digitiser for a survey firm. After months being unemployed, the same firm has hired her again, allowing her to telework from home.

The most difficult part of Florencia's daily life is loneliness. It is difficult for Florencia to maintain social relations outside the care relation; she centres her social life in her relationship with the elderly due to the extensive number of hours care entails. For this reason, the emotional well being of the carer depends heavily on her relationship with the person in need of care (Raschick and Ingersoll-Dayton 2004). Florencia is happy to be her mother's carer despite her situation of isolation because she has been able to maintain the good relationship with her mother. The good relationship is due to the fact that Florencia sees her mother as her child. Role reversal is a source of fulfilment for Florencia.

> *I don't have any children, but I can imagine it's just the same. I care for her [her mother] like a mother cares for a child. I get her dressed, give her bath, cook her food and give it to her in her mouth because if she tries to do it by herself then it's a mess. I watch her while she plays with the domino pieces moving them from one side to another. I laugh when she sings funny things. She is like a child and for me it's gratifying to see she is well cared for. Maybe I cannot get out of the house and I cannot see people, but I feel good with what I do and how I do things. (Florencia)*

Claudia's mother recently began needing care. The reversed relationship that has resulted makes Claudia sad and uncomfortable. Before becoming her mother's carer, Claudia, already in her 50s, always felt like her mother's child, and she enjoyed being supported and cared for as a child. Today, her 86 year-old-mother has become the daughter of their relationship, which disturbs Claudia deeply as she is not used to treating her mother like a daughter.

> *You become the mother and she becomes the daughter. I see it that way. For me this is complicated because I am not used to this relationship when all my life I have had an enormous reverence to my mother. My mom was always the one with the last word, her*

> *words were like sacred to me. And now I have to tell her 'mom do this' or 'don't do that' and I sometimes feel bad and guilty because in the end I am not her mother, she is my mother. Now she has started talking back at me every time. I tell her, for example, that she needs to that her medicine and she replies 'yes mom'. (Claudia)*

Aggression to the elderly in need of care

The care relationship, conditioned by the dependence of the elderly, moves always in a delicate balance, where the asymmetry can be processed in a space of love and dedication, or into the abyss of fatigue and hostility (Abusaleme and Caballero 2013).

> *I sometimes look at her when she is sleeping at nights, and then in those moments I think 'Oh! How mean I am with her' and then I feel sad, and regretful, and sometimes I even cry because I feel bad, it happens to me when I see her sleeping that I regret not being nice to her, because in the end being as dependent on me as she is not her fault. (Sara)*

The fatigue and loneliness that characterise the daily caregiving routine can erode, change and damage even the best relationships. Some carers, overwhelmed by their care situation lose their patience with the elderly and react in ways that, after the fact, makes them less satisfied with themselves and with their roles. When relationships deteriorate and the carer loses patience, he or she can become aggressive, mean or less nice than what she or he was used to be or would like to be with the elderly. These episodes make the carer feel guilty and regretful. The quality of the relationship will affect the quality of care, and carers, aware of this, will suffer when they note that they are not providing good quality care.

Blanca is 78 years old and cares, by herself, for her 102-year-old mother. She is tired. When she needs respite she prays the rosary but she usually falls asleep while praying. Although her historical relationship with her mother was self-described as *normal*, caring for her mother has damaged their relation. Blanca confesses she sometimes gets mad and is mean to her mother. She says she screams to her mother when she refuses to eat, for example. Blanca says her mother gets angry when this happen and their relation spirals downwards. Her mother then tells whomever she sees (her son who visits her on Mondays, for example) that Blanca is a bad carer, and Blanca gets madder. Then Blanca feels guiltier, the intensity of her experience increases and her experience becomes overwhelming.

Fátima has always been close to her mother, they have almost always lived together and had a good relationship in the past. She is the youngest of a phratry of six and the last one to leave her mother's home. Fátima's mother is the person Fátima sees the most, practically the only person she sees on any given day. The everyday routine of her mother's care without the support of her siblings makes Fátima more irritable towards her mother and their past good relationship has changed. Fátima regrets the change in their relationship, but she finds it difficult to revert, she is tired and any effort is very difficult for her.

> *We got along better in the past but now she sometimes tells me I'm very irritable, that I 'send her to fry monkeys in Africa' [a Chilean expression to tell someone to go far away for a while]. It's exhausting for me, she asks me things all day. And her medicines, because she takes six medications a day, then I have my mobile phone full of alarms and reminders to tell her to take her pills, I'm tired of that, and I sometimes lose my patience. It's that I start at 7h in the morning every day and I don't stop until 22h at night, and then the alarm sounds again and I start all over again. I am stuck in the routine of her care. (Fátima)*

Lucía is also sometimes mean to her father. They started cohabiting a year ago. Prior to that, her elderly father lived in the countryside alone; his wife passed away five years ago. Lucía and her father's relationship has been in adaptation since they began cohabitation. According to Lucía, her father was used to be attended by his wife. When he widowed he established a routine and schedule that is incompatible with Lucía and her daughter's habits. For example, her father likes to watch television with a loud volume late into the night. Lucía gets mad with this habit because he is not deaf and his room is right next to Lucía's daughter's room and she wakes up early to go to school. He was also used to permanent service by his wife and expects Lucía to do the same. Although Lucía is very engaged in her father's care she refuses to do some tasks, like ironing all his clothes, as her mother used to do. Lucía gets mad with her father sometimes: "*I honestly don't have time to iron, so he has to wear his clothes like that, he has to adapt to my way of life, to my schedule".* She admits that their relationship has changed and that, little by little, they are getting used to the care situation.

> *Yes, it has changed our relationship, but not in a bad sense, I've learned to adapt. I am very energetic with him sometimes, I'm like the crafty mom because my dad is stubborn. For example, my dad just did not have the habit of bathing every day, but I say to him that the body needs a bath and I have to explain things like I would to a child, and then that's when I have to raise my voice, at times I realise I am shouting, but it is the only way he understands me, that he listens to me and pays attention to what I am saying. (Lucía)*

Only feelings of regret emerge after a carer realises she or he has been mean to the elderly, contributing to carer's negative feelings towards care and towards themselves. Many carers in the study mention they lose patience with some elderlies' behaviours and that, as a result, they are not nice with the elderly. Carers were generally upset when talking about these moments.[83]

Research has found that when a person being cared for is viewed as incompetent, or lesser in every way, becomes a target for abuse or mistreatment. The pressure of unsupported caregiving may increase the likelihood that a care recipient will be abused in some way. The abuse of

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[83] There was no case in the study that acknowledged having mistreated the elderly. The purpose of the study was not to investigate elderly mistreatment, reason for which the researcher did not probe further into the issue. However, regret for bad care was a recurrent feeling among carers. Further research should focus on elderly mistreatment, a phenomenon with deep consequences for the elderly, the carer and their relationship.

power can go in the opposite direction as well, subjecting the caregiver to the "tyranny of the ill" (WHO 2001).

Absorbed by the care relation

For all caregivers, no matter their situation and the relationship they have with the elderly, care is perceived to curtail their free time. A large majority of carers, no matter their age, economic condition or gender, would like it to be different. They would like to have some time for themselves and be able to take vacations once in a while. Despite this generalised feeling of lack of free time, some carers feel completely absorbed by the care relation, increasing their feeling of pressure. Sara is one of them. She feels *sequestered* by her mother, not because of the amount of time she spends with her but because of the relationship they have.

> *She [her mother] is very attached to me. My mom (she exhales) absorbs me very, very much, and she wants to know everything, everything, why did I do this or that, she wants me to stay with her, and even further, she wants me to go to bed at the same time she goes to bed! So then that makes me angry, but then I realise I do not have to be that way… (Sara)*

When carers feel absorbed by the elderly it is because they think that the elderly has intentionally some responsibility. Absorption emerged in situations when the elderly is not severely physical or cognitive dependent and is still autonomous in some daily life tasks. Sara gets mad when her mothers asks her, for example, if she will go to bed soon or when she shouts from her bedroom to ask Sara what she is doing. Sara struggles when her mother, husband and children had plans to go out and at the very last minute her mother decides she doesn't want to go. Sara has to stay with her.

Bernardita, the main carer of her lowly dependent father, thinks her father has a strong emotional dependency on her. It frustrates her and tires her. She is single because she decided to dedicate herself to her father's care when he first developed stomach cancer ten years ago. She feels this decision, although taken by her, is unfair and frustrates her because it meant that she never married and had her own family, as her sisters do. To a large extent, the relationship she has with her father explains where these feelings come from.

Sporadically, Bernardita' sisters offer to take her father out. But he refuses, under the excuse that if Bernardita doesn't go he will not go. The rare occasion Bernardita has respite from her caring duties are wasted because her father wants to be with her all the time. The only respite left for Bernardita is her job as a cleaning lady. Bernardita's father's emotional dependency and her need for respite explain why Bernardita likes her job. The absorption of her care relation explains why it is not exclusively the pay, or the fulfilment of the job, but respite that explains Bernardita's choice to work.

> *He only wants to be with me. He goes to my sister's house, but only if I go too. He is too dependent on me. He goes everywhere but only if I go. And this is getting worse and worse, everyday he becomes more like that. (Bernardita)*

For Bernardita the most difficult part or her role as a carer is the relationship she has with her father. Not because it's a bad or conflictive relationship because they actually get along well, it's the emotional dependency that wears her out.

> *He [the elderly father] gets complicated because he doesn't like me getting out of the house. In that sense my life is complicated. I don't know if it's because he doesn't want to be alone or because he is afraid that I am doing something else, that I have another life. I thinks that that's what he deeply has in his heart, because every time I get together with my friends, which is really not often at all, he is not happy after. (Bernardita)*

This relation of emotional dependency also explains why Bernardita, although living in a municipality that offers support programmes for the elderly and for the elderly care and is eligible to participate has never used this support. Her father refuses to participate in any activity that leaves him without his daughter.

> *We only take some medicines from the primary health centre, but that's the only help we get. We have never gone to the municipality, I tell my father we should go but he doesn't want to, he asks how can he go alone, without me. He sees me like his mother, his wife and his grandmother, like all those roles together. He is too emotionally dependent on me. Sometimes one of my sister calls him to invite him to have an ice cream or whatever and he says 'no, I have to ask Bernardita first'! Can you believe that? (Bernardita)*

Ana María's case shows how the feeling of absorption is not a matter of hours spent with the elderly or proving direct care. Absorption is a characteristic of the relationship. Ana María comes from a high-income household and cares for her mother who is in a nursing home. She is the only among her phratry living in Santiago, where her mother lives now. She visits her mother every other day. Every time Ana María leaves her mother says: *"Are you leaving already?"* Ana María feels bad and angry. When her father died, four years ago, her mother started feeling lonely and requesting more company from her children, especially from Ana María. Using Bernardita's terminology, Ana María's mother became increasingly emotionally dependent. Ana María's mother, who used to be a very independent woman, began calling Ana María day and night asking for help in different aspects of life. Then the demands for help became more complicated: *Come and pick me up, it's an emergency.* But there was no emergency; she just wanted Ana María to be close to her. This was before the elderly entered the nursing home, when she lived in San Rodrigo, a five-hour drive from Santiago, where Ana María lived. Now that the elderly lives in a nursing home in Santiago, she has become even more attached to Ana María who is the only one who visits her often (her brothers live in San Rodrigo and her only sister lives in the United States).

> *I think my mom doesn't even notice that she is affecting me and restraining my life this much… I had a grandmother, my father's mother, who became like my mother is now, she felt that everyone should attend her, that the whole world should move around her. For example, even in periods when I visit my mother very often she will say to me when she sees me appear in her bedroom 'Oh, my daughter you finally appeared'. That gets me very angry. (Ana María)*

For Ana María, feeling absorbed by the relationship with her mother, makes her experience care very intensively. *"Elderly care is atrocious for the children,"* says Ana María when describing her care experience. Despite this pressure, she would never abandon her role.

> *I could not stop [being the main carer]. I do it for her [her mother]. But I confess there are days that I'm so tired and I just wonder what sense there is that she is alive (she cries). Besides, I love her, I could not abandon her, for example, I do not understand how my brothers can pass an entire month without coming to see her. (Ana María)*

7.2.2 Relationship with siblings

The presence of brothers and sisters can be a resource for main carers but it could also be a source of pressure, depending on the relationship between the siblings. Because families are an important source of social and emotional support to their members, as well as a potential source of pressure, conflictive relationships among siblings can have damaging effects for family caregivers of an elderly (Scharlach et al 2006). Families disrupted by conflicts or other signs of family dysfunction provide less assistance to members in need of help (Lieberman and Fisher 2001) and less social and emotional support to those family members who have primary care responsibilities (Gaugler et al 2003). Family dysfunction can undermine the family's competence as a supportive entity for its members (Weihs et al 2002), resulting in an increased distress for those family members who have primary caregiving responsibilities (Scharlach et al 2006). Old loyalties and rivalries between siblings, problems and strengths stand out when an elderly parent is in need of care. Relationships among siblings, like the relationship between the carer and the elderly, do not arise afresh when elderly dependency begins but are part of a natural continuum of the family's history (Brody 2004). Larger families can entail conflicts related to the negotiation of care responsibilities among members, contributing to caregivers' negative care experiences (Davey and Szinovacz 2008).

As described earlier, the social network is not automatically converted into support. The way carers rationalise their siblings' support or absence of support helps explain how carers experience care.

Conflict among siblings regarding the appropriate type and amount of support for the elderly care can go against caregivers' normative expectations, arousing caregivers' frustration and anger (Semple 1992), as is the case of Fátima, Trinidad and Ana María. When carers find their siblings do not have a valid or legitimate excuse for not cooperating (to their expectations) with elderly care, conflicts arise, increasing the intensity of the caregiving experience, as is Fátima's case. Sometimes, having a negative relationship with siblings worsens the relationship between the main carer and the elderly, as in Fátima's and Ana María's case.

The organisation of vacations is also a common source of potential conflict among siblings; main carers want to take vacations with their nuclear family and have a respite from elderly care but it's not easy to convince siblings to assume the role of main carers of the elderly parent, even temporarily. Either caregivers haven't taken vacations since they took up their caring role or, whenever they do take some days off, it generally involves a conflict with siblings to organize elderly care during this period.

The main caregiver can maintain a good relationship with non-collaborative siblings if he or she considers no one else in the phratry is competent to provide care, as in Lucy's case. Having a good financial situation can reduce tensions between siblings and maintain a good relationship, as seen in Josefina's case.

For Fátima, a middle-income woman, the most difficult part of her situation as carer of her elderly mother is dealing with the fact that her siblings do not take part of the care arrangement. She is constantly angry at them, a feeling that also affects the relationship with her mother and with her own nuclear family. Her historical cohabitation and the historically good relationship she has had with her mother are the reasons why she assumed the role of her elderly mother's primary caregiver. The role now poses pressure in Fátima's life because her siblings do not help with the elderly care as Fátima expects.

Fátima also wanted to take ten days off with her nuclear family. She invited her siblings over house to talk to them. When Fátima told them about her plans, no one offered to care in her absence.

> *So I told them, ok. I am going to go even though my mom stays here alone, and I asked them to leave the house. For a week I felt a strong pain in my chest, I felt like I was abandoning my mom for these 10 days, but no, I have been caring for her for years and I just wanted 10 days of vacations with my husband and my kids… those are the kind of things that make me really angry, the conflict, the fights. (Fátima)*

Fátima finally went on vacations, but only for five days, the time her mother could be under one of Fátima's daughter's care. For the other five days, no one among her siblings was available and Fátima could not abandon the responsibility she felt for her mother's care.

Trinidad is the main caregiver of her 98-year-old mother who has had severe dependency for four years. She also cares for her oldest brother who is diagnosed with Parkinson's disease and has physical and cognitive dependency. Her brother gives Trinidad a hand once in a while when she needs to do physical efforts. The other six siblings, three men and three women, only offer financial support. Trinidad is in a big fight with her sisters for not providing her support with caring tasks. She never refers to any type of conflict with her brothers who, like her sisters, don't contribute to caring tasks. Although there is no legal duty in Chile to care for an elderly parent, she found a lawyer and sued her sisters for the lack of support.

> *Nobody wanted to take care of my mom. I had a tremendous fight with my sisters, I'm up in court with them, court, and do you know what it means to go to court? The judge stated that they have to come Thursdays, Fridays, Saturdays and Sundays to care for her and they do not come! No one comes. They come together once in a while on a Saturday and then go. (Trinidad)*

Trinidad is in her 60's. She struggles with the physical fatigue of caring for both elderlies all by herself, but she also struggles with the anxiety of seeing her mother abandoned by the rest of her children the last years of her life. For Trinidad, her mother had a very good relationship with her younger daughters and gave everything to them, much more than what she gave to Trinidad, because they are younger and by that time her mother had a better financial situation than the one she had when Trinidad was young. Trinidad remembers her childhood as sad and lonely; her father was an alcoholic and he was never at home. Her mother was dedicated to raising younger children and was abusive to Trinidad, both physically and psychologically. When she was eight years old, Trinidad had to work to contribute money to the house. When Trinidad was a teenager, she got pregnant and her mother kicked her out of the house. Trinidad came back when she was in her thirties. At that time, Trinidad enrolled in the communist party. When her mother found out, she feared that the military government would harm the whole family, and kicked Trinidad out of the house once again. Trinidad has never resented her mother and every time her mother opened the house for her she would come back.[84]

It's not the past relationship with her mother, her postponement or her own deteriorating health that makes Trinidad suffer. She has been caring for her mother and brother for four years; the first three and a half she moved in with them and went back home to her own house and husband on weekends. The doctor has told her to take some distance from caring; she collapsed with the care responsibility and has now moved back with her husband. She visits her mother at lunchtime every day; a paid caregiver cares in the mornings. She and a brother pay for the external caregiver.

It's the relationship with her sisters that makes Trinidad suffer. For Trinidad, the relationship with her sisters is different because she understands the difficulties her mother went through and which explain that she was not a good mother to her. Trinidad cannot understand why her sisters have run away from her mother now that she needs care, given that she was a good

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[84] Though Trinidad never frames it this way, she may play the role of the 'rejected child' described by Brody (2004). It is that of a child among the phratry who feels rejected or the least loved and therefore provides care for her parents, hoping, deep down, that her mother will finally love her.

mother to them. Trinidad's deepest constraint is rooted in a context of relationships marked by a difficult life history.

> *My younger sister has made me cry. It gives me great pain and anxiety to see what they did with her mother. My mother, who gave everything to them. You know what my sister said? And I have heard her with my own ears, that she has a hard heart and that she doesn't care seeing my mother like this. (Trinidad)*

Ana María feels very absorbed by her mother's care, as described earlier. From more than twenty years her only sister lives in the United States, making Ana María her mother's main caregiver. Ana María's mother lives in a nursing home. Ana María's sister comes every summer for a month to give Ana María some respite. Ana María is satisfied with her sister's support and has a good relationship with her. She would, however, like more financial support from her brothers, but they refuse to give her monetary compensation for the work she does. As mentioned earlier, she met with her brothers and discussed the possibility of being paid by her brothers for the work she does for their mother. She is using her time; she has postponed many of her personal projects and spends money on the weekly psychological treatment she receives since becoming her mother's carer.

For Ana María, her mother's care is a shared responsibility, not exclusively her own. Her brothers did not react favourably to her suggestion to pay her; they found it ridiculous, they did not understand that care for their elderly mother was seen as work that deserved a salary. The issue was not discussed again and Ana María regrets having even raised the issue. Ana María felt ashamed – her cheeks become red when she tells the story, showing she is uncomfortable with the current care arrangement and her siblings' level of involvement. Ana María still recognises that the work she does managing and organising her mother's care should be paid by them. She feels sad and angry for her brothers' lack of understanding and support. Their relationship got damaged, increasing the frustration Ana María feels towards her care experience.

Conflictive relationships between the main caregiver and the other siblings mediate the relationship that the main carer has with the elderly in need of care (Scharlach et al 2006). This was seen in Fátima as well as in Ana María's case. Both caregivers had positive relationship with their respective parents in the past. The difficult relation they have with their siblings make them angry and frustrated in their role as main carer, eroding the relation they have with their mothers.

Rebeca's and Catalina's experience is the opposite of Trinidad's or Ana María's. Both Rebeca and Catalina come from high and middle-high income households. They maintain a good relationship with their sisters even though they do not participate in the care arrangement.

Neither Catalina nor Rebeca – contrary to Ana María or Trinidad – expect a different involvement in the care arrangement by the part of their brothers or sisters and this difference in expectations goes back to the historical relationships with the elderly and the siblings.

In the past, both Rebeca and Catalina had a positive relationship with the elderly, a better relationship than the one their mothers had with their non-caring sisters. They feel they received more than their sisters from their parents; this justifies their higher involvement in the elderly care now. This compensation makes for an acceptable excuse for their siblings' lack of involvement.

With no mismatch in expectations, there is no source of conflict. Responsibility for providing care may be divided disproportionately among siblings based on the history of the relationship between each sibling and their parent (Connidis and Kemp 2008) and depending on the acceptability of this, caregivers will have, or not, a conflictive relationships with those among the phratry not providing care.

Catalina, a middle-high income 55-year-old woman is the main carer for her elderly mother with whom she lives. She has two sisters and three brothers. One sister, Fernanda, is very involved in her mother's care, but Grace, the eldest, is not involved at all. Catalina has been able to keep a good relationship with Grace despite her lack of involvement, because she understands Grace's reasons for being far from her mother. Catalina was born when Polio disease was eradicated from Chile, but she was one of the last cases of incidence of the disease. Her parents' attention when their children were young was directed almost completely to Catalina, leaving the rest of the siblings to fend off by themselves or under Grace's care, the eldest daughter. Catalina greatly values her parents' dedication to her. She recognises that her mother was particularly mean to Grace during their childhood.

> *It [elderly care] is very difficult; each day is full of difficulties related to her [her mother's] disease and the reactions she has been having lately as a result of dementia. I live around her needs. I receive support from my siblings but not from Grace, she has a very bad relationship with my mother and although I would like to receive support form her I am on her side. My mom is not precisely a nice person, not even to me. She has been very mean to Grace throughout her life and Grace, now, she kind of has an armour; she has turned into a very cold person. My sister lost a son to pneumonia. The child died in her bed, he went to her bed and after a few seconds Grace touched him and he was cold, he was dead. My mom told her one day, 'if he had been under my care he would have never died' that's how mean she can be. (Catalina)*

Catalina's case shows how the relationship carers have with their siblings, and especially sisters, depends on many factors that come from a long history of events, relationships and feelings. The relationship caregivers have with their siblings that mediates their experience goes well beyond their involvement in the care arrangement. The manoeuvring that may precede the resolution of a care scenario as it is hashed out among siblings offers insight to understand the sibling relationship in caregiving (Silverstein et al 2005).

Having a good financial situation to pay the costs of the elderly care is an objective resource for the caring experience, discussed in Chapter 6. A good financial situation can also become a resource in a more subjective dimension, as it can reduce the tensions among siblings and maintain a good relationship. A good financial situation – in which the elderly in need of care can pay for his or her care – reduces the need for sibling support. Josefina, a main carer from high-income income household is clear in recognising that the good relationship she has with her siblings is sustained, to a large extent, on the fact that their parents' pensions and savings are high enough to cover care costs and that all members of the phratry have a good financial situation.

> *We were never a troublesome family, we have accepted each other as we are, and we are very different, there are ones who are more intellectual, others more athletic, others more sociable, but we have never criticised each other, criticism was never a way to go in my family. We were not close friends going about side by side, but we knew and know we are a group. Knowing that, at this stage in life has enabled us to reach agreements in our parents' care, especially because of one fundamental thing: our parents, they are still able to financially maintain themselves with the economic means of our dad, or I should say that that's the most important issue regarding the peaceful relationship among siblings. I know there are cases in which the siblings have to put money but not all do that, and there are some that can and others who cannot, and there's a huge problem when there are not enough funds. In my parents' case, they have been maintained thanks to their finances and I think that's the pillar of the relationship we have nowadays. (Josefina)*

The main caregiver can also maintain a good relationship with non-collaborative siblings if he or she considers no one else in the phratry is competent to care. These caregivers account for caregiving as an individual activity for which they are especially suited excusing the rest of the family for not providing care as much as they do (Willyard et al 2008).

Lucy and Pilar both have a sister and a brother. Pilar shares some of the care work with her sister but she does most of the work. Lucy does all the care work herself. They don't expect the arrangement to be any other way because they think that they are the best suited for it. Pilar says she has always been the "*official family carer"*. She has been the main caregiver of her mother before she died, and she supported strongly her cousins' care when their father was dependent. The skills for caring she has acquired throughout these experiences has given her a special recognition among her relatives. Today, if a nephew or niece needs an injection, someone has a wound to clean or someone suffered an injury, they will call her. Pilar accepts she is more involved in her father's care than her sister is. She also has a better relationship with him, validating further the fact that she, and not her sister is the main carer. This imbalance in involvement in care work is not a matter of conflict in their relationship.

Lucy does not receive any support from her sister. Although she faces many daily constraints in being both her mother's and father's main and only caregiver, she wouldn't feel comfortable if her sister stays caring for her parents. Lucy thinks her sister has no competencies to care for their parents and she is the best suited for it.

> *My sister is not very reliable... Or not, maybe is that I consider myself very apprehensive with the two [with her parents], then I think that nobody will care for them like I do, so in that sense I am, I don't know... as I told you, when I was working for a year in the North [of the country], it was my son who was in charge of the house and of them [the elderlies]. My sister barely came, my sister has never been good housewife. I think that this was also a factor on why she divorced. (Lucy)*

Lucy's and Pilar's, expertise in elderly care – and their sister's lack of comparable skills – serves as a valid excuse for her sisters not participating in the elderly care as they do. It contributes to decreasing the potential conflict in their relationship and the intensity of their experience.

In this study, common conflicts among siblings are not related to the decisions regarding the elderly care, or to the negotiations involved in the process of assuming the carer role, since most main carers assume all the care responsibility without sibling support, and sibling support would entail siblings to take part of the decisions regarding care. The biggest source of conflict with siblings comes, by contrasts, from siblings' dissociation from elderly care, and the fact that there is only one in the phratry, the main carer, who renders most of the care to the elderly parent in need of it. Money matters related to the elderly care costs is also a source of conflict between main carers and their siblings, but not among high-income households where the elderly's pensions and savings are more likely to cover their care expenses.

There is no 'one case fits all' or a straightforward explanation for the main carer-sibling. This study's cases show that having a good relationship with siblings makes a difference in carers' experiences. Though a good relationship with siblings does not make the care experience absent of difficulties, it makes it more bearable through a reduction in negative emotions.

7.2.3 Relationship with siblings-in-law (when caring for a parent-in-law)

Three cases in this study are the main caregivers of an elderly parent-in-law who also had siblings-in-law. The other cases of daughters-in-law caring for an elderly parent-in-law were married to a single child (which also explains why it is them and not a daughter who became the main caregiver). In these three cases there was conflict, albeit with different intensity, with the siblings-in-law.

Andrea's conflict with her siblings-in-law that causes the least pressure compared to that of other carers in the study. She is the main caregiver of her mother-in-law and her aunt-in-law, both elderlies with Alzheimer's disease. Andrea does not have paid employment; she does multiple care work at her house, caring for the two elderlies and her granddaughter. Her husband participates actively in the care arrangement. She has only one brother-in-law (no sisters-in-law). Andrea does not expect her brother-in-law to provide direct care. She neither expects financial support because the elderlies' pensions and past savings cover the care expenses. Andrea does not feel she should be compensated by the care work she does; she feels she receives compensation by living in the elderlies' house which has been a strong resource for raising her own daughters there. Andrea and her husband would like that her brother-in-law provides emotional support to them and emotional care to the elderlies, none of which he does. He only visits the elderlies once or twice a year. As Andrea's expectations towards his participation in the elderly care are low, they are easy to fulfil, or of less importance, diminishing the potential conflict.

Consuelo, from a middle-income household, works as a school secretary and lives with both her parents-in-law. Paz, from a low-middle-income household works as a street singer. Both are the main caregivers of their cohabiting elderly parents-in-law. For both Consuelo and Paz, the lack of support from their partner's siblings negatively affects their relationship with their siblings-in-law, and therefore, their care experience.

Money was an important issue in these conflicts, especially in Paz's case, who does not receive any monetary support from the rest of the family although they face important economic constraints: "*What can one do with the 85,000 pesos per month [120 euros]*" says Paz referring to the elderly pensions her parents-in-law receive.[85] Paz brought the elderly couple to live with her four years ago, when she realised that their health had deteriorated and that they could no longer live alone. By then, the elderly couple lived with one of their daughters. Today, her siblings-in-law are mad at Paz and her partner. They say she and her partner want to keep the elderly just to receive their pensions, something Paz finds ridiculous because the pension cannot even cover for the medication they need. Money has always been an issue between her in-laws, which explains part of the magnitude of the conflict they have today.

> *When the old folks were well, they had some money and they gave it all to their children, they gave them land and money to build a house. This is when the old folks were in their youth, in their healthy years. And what happened is that after the couple of old folks did not have any more money, and they actually had nothing, uh... their children sort of rejected them. They [the elderlies] went from house to house. When I brought them here she [her mother-in-law] weighted 36 kilos, she was a drug addict. She drugged herself with different medications; she was once poisoned and almost died, and all this happened while under the care of a daughter, the only daughter they have. When this happened, I realised they were being abandoned, her daughter was leaving them to their fate, if they lived, good, and if they died, good too. Then I talked with my*

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[85] The interview was carried out before the Basic Solidarity Pension was increased to 95,536 pesos a month (135 euros).

> *with my partner, I told Angel [her partner] I could care for them. They had a small house they sold two years before coming here with us. So in no circumstance did I do it because I wanted to keep their house or their money. Hey, his [Angel's] brothers and sister were angry at us because we brought them here! But what can I do if they were abandoned? What else could we do? I am not able to leave even an acquaintance abandoned, nor a friend, not even an abandoned animal, less would I leave them [the elderly couple]. Then I took care of them from A to Z, until the end, without thinking on the consequences, and this decision has not brought me a good life because they [the siblings-in-law] have declared war on us... they talk behind my back saying that I'm taking advantage of them [the elderlies] or something like that because they each have their salary [pensions] and I am taking it. (Paz)*

Consuelo lives with her nuclear family and both her elderly parents-in-law need of care. They have cohabited for 30 years, when she married her husband. The elderly woman has a severe dependency, and the elderly father-in-law a moderate dependency. The mother-in-law started needing help eight years ago. The elderly couple has three children, two daughters and a son, Consuelo's husband. The management of the elderly care relies on Consuelo, and during the day a paid caregiver provides care. She finds her management role very difficult, as mentioned in Chapter 5. When Consuelo comes back from work she takes the relay, with the support of her husband and children. Elderly care costs are paid with the elderly pensions and money coming from the three children. Her sisters-in-law live in the same neighbourhood. They work part-time but they always have an excuse when Consuelo asks them to stay with the elderly. For example, when the paid carer cannot come, Consuelo has to stay and miss a day's work because no one else is available. When the elderlies did not need help and were healthy, the family relations were *"normal as in any family, with minor disputes once in a while but no more than that."* When the elderlies where healthy, their daughters and granddaughters visited them more often. It has been difficult to assume that their mother is severely dependent and they use it as an excuse for not visiting or helping more often.

> *For the two sisters it was difficult to assume that their mom could no longer be alone, that she needs help with everything, that she has to wear diapers, be dressed, bathed, and fed by someone else. (Consuelo)*

Consuelo finds it unfair that they use that as an excuse, because it's not easy for any of them, but it's an obligation. Consuelo gets confused when trying to understand and explain why they don't support the elderly care and when trying to understand her own feelings towards that lack of support.[86]

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[86] This study does not capture the motives why siblings-in-law do not participate in the care arrangement beyond the perceptions of the main caregiver, as the main focus of this research is to study the main caregiver's experience. Other research has analyzed the siblings' involvement in the elderly care and their motives. For example, in families where one sibling resides with an aging parent in need of care, siblings expressed dissatisfaction and justify their lack of support because they feel excluded by those who maintain control over decisions pertaining to parents (George 1986). Lashewicz and Keating (2009) also

> *Ah! It's so difficult! The thing is that one always involves feelings, involves many other things so it's very complicated to really understand and judge the whole situation. I think that for everyone it would be easier if we were all involved. We wouldn't fight and at the end the elderlies themselves would be happier. But when you have a sister-in-law who doesn't help and does not have money to cover some of the costs, another one who does not receive the support of her nuclear family so physically the care of the two elderlies alone becomes practically impossible, but she cannot, I don't know why, ask more emphatically to get some help. In our case my husband and children cooperate, but they are the only ones, none of the rest of the grandchildren or brothers-in-law support with care. (Consuelo)*

A year ago Consuelo and her husband tried to organise care during weekends and holidays, when there is no external paid caregiver. They arranged a system of turns with each sibling providing care and sharing each period. It didn't work. Her sisters-in-law did not stay long enough during the day. Sometimes, when Consuelo's and her nuclear family had gone out of the city, they fond the elderly were left alone in the house. A conflict with her sisters-in-law emerged. Though the system of sharing weekends continues, Consuelo knows that the elderly are alone a large part of the weekend, especially at nights, when Consuelo and her family are not in the house and a sister-in-law is supposed to be there.

> *If it's your turn on a weekend, for example, you are supposed assume the role on Friday afternoon and finish on Sunday night. But is has never been like that. One of the daughters has slept over twice in six or seven years, and the other has never stayed. Then the two elderlies are left alone, so at the beginning we assumed the role when it was not our turn, but we do not do it any more, we try to have colder blood and think that if it's not our turn we won't be responsible [of the elderly care]. But it's not easy, you have to be super cold and pray to God nothing will happen to the elderlies while you are not there. In any case, it wouldn't be of our responsibility but that of the one supposedly in charge. They were too spoiled with the fact that we were always there. And summer vacations are also a motive for conflict. (Consuelo)*

The difficult relationship with her sisters-in-law puts of pressure in Consuelo's daily life. If she were able to go back in time and re-make the decision to become the main caregiver she would decline. It's too unpleasant and her siblings-in-laws do not appreciate it. Quite the contrary, her sisters-in-law only criticise her for the way she cares for the elderly. Other research has found that siblings-in-law were troubled by the pre-eminence of decisions made by the main caregiver, explaining their bad relationship (Cicirelli 1995).

Having siblings-in-law when being the main carer for a parent-in-law is a vulnerable situation in terms of the relationships. It can increase the intensity of the care experience, by producing a strong feeling of pressure in the main carer. In this study, money was an issue that causes trouble among siblings-in-law and the main carer, as well as the mismatch between the main

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find that one source of sibling dissatisfaction with the dominating influence of other siblings was siblings' beliefs that the dominating sibling had separated the parent from other siblings.

carer's expectations and the actual engagement his or her siblings-in-law have, in addition to the constant criticism and lack of recognition that the main carers receive from their siblings-in-law.

7.2.4 Relationship with the nuclear family

Caring for an elderly parent or parent-in-law means that time, attention and energy is put on the care work. The dependency of an elderly needs a rebalancing of roles and relationships; whatever the pace of the readjustment, the caregiver's couple and their children may compete with the elderly for time and attention (Brody 2004). For the nuclear family, a main carer becomes the 'less available mother', the 'always tired partner', a source of constraints in taking vacations as a nuclear family, changes to the house infrastructure that affects the comfort of family members, and the constant conflicts with the rest of the extended relatives. These changes affect the nuclear family relationships.

Not all changes within the nuclear family relations are negative. The relationship between a caring mother and her daughters could strengthen, moved by a sense of female complicity. It could be that the carer's children and/or partner collaboration with the elderly care creates positive feelings of gratitude and love in the caregiver.

Whether positive or negative, all cases in the study admitted that their relationships with their nuclear family changed since they became the primary carer of the elderly. It did not unequivocally deteriorate. In this study, the most common transformation consists of a mix of negative and positive changes in the relationship. In some cases, care ameliorates or strengthens some relationship within the carer's nuclear family. Changes to nuclear family relationships were accentuated when carers and their nuclear family cohabit with the elderly in need of care. Changes are more important in low- and middle-income families because of their limited means to delegate care.

Carers' relationship with their children

In general, the children of a main caregiver receive less attention, as their parent is dedicated to the elderly care. This can cause a distancing in their relationship. Carers usually feel the distancing. Both Andrea and Eugenia regret the distancing that results from care, especially at the beginning of the elderly care path. This regret increases their feeling of pressure. For María, however, caring for an elderly has strengthened the relationship with her teenage daughter.

Andrea is a middle-income carer of her elderly mother-in-law and aunt-in-law, both with Alzheimer's disease. She lives with both elderlies from the day she married. Care is demanding for her, Andrea receives no support other than her husband's. Andrea has two daughters: one is 21 years old and the other 16. The youngest, is also the mother of a baby. Andrea is also her granddaughter's main carer. Andrea feels guilty of her teenage daughter's unplanned pregnancy; she thinks that due to her dedication to elderly care she left her daughters aside. She thinks that if she had been closer to them, and especially closer to the youngest, she wouldn't have gotten pregnant. The existence of the baby is a concern for Andrea, she sees her daughter's future hindered as a young mother. Andrea offered to become the baby's caregiver as well, so that her daughter could finish secondary school and, hopefully, continue to University.

Offering this possibility to her daughter is a sensitive issue for Andrea. She did not finish secondary school as a teenager because she married and had her first daughter at a young age. As an adult, she spent two years studying in the evenings to obtain her school diploma. Her dream is to go to University one day. This dream was postponed by elderly care. She experienced the lack of opportunities associated to both the caregiver role and the lack of formal education; she does not want the same future for her daughters. She has added all baby care to her caring tasks; she will do it as long as necessary so that her daughter can become a University graduate, have a profession and access the good quality employment she could not.

Eugenia has been caring for and living with her 91-year-old mother for seven years. Eugenia lives with her husband and their two children as well. She regrets leaving her children aside when she became her mother's caregiver. Now that the children become independent, she regrets having missed part of their growing up.

> *The last years of my daughter's school and especially those of my son, I couldn't be with them. I couldn't be with my daughter for the activities they did in the school, and my son I should say that he was totally left alone. That is what I regret. I don't know if some day I will 'have to pay' for it, I really hope not. But they have never said anything to me, I think they understand. Ah! Yes, my daughter once got very mad at me, it was the day of the earthquake in 2010. They were all getting out of the house [it's dangerous to stay inside] and I was not moving, I was all the time next to my mother's bed. I didn't want to leave my mother alone in case something happened to her. But my daughter got furious, she shouted at me that I shouldn't forget that I have a family that needs me and that the grandmother is not the only person that needs me, that they also need me. I said 'daughter, I love you very much, but if something happens to my mom during the earthquake I will carry a guilty conscience forever, so sorry, I will stay'. That was the only time my daughter said anything. They suffered a lot because I was not with them. Other than that fight, she has never said anything to me like that again. Actually, my daughter is the only person that gives me a hand once in a while with my mom's care, and she is the only person in the world to whom I talk about my sadness and anxieties. (Eugenia)*

The distanced relationship between Eugenia and her daughter has now shifted with the rise of complicity between the two. Although Eugenia regrets the distancing with her children during the last years of school, the complicity that she now has with her daughter has allowed her to recreate their relationship. Their relationship, now, is closer to friendship, in which she, the mother, talks to her daughter about her negative feelings and then she feels relieved.

The complicity between Eugenia and her daughter, and the shift in their relationship towards one commonly seen between peers is observed in other carers as well. The fact that carers are occupied and absorbed by elderly care duties reduces their opportunities to maintain social relationships with friends. This, added to the cultural belief that care is a female issue, makes the care mother and daughter relationship one shaped by understanding and complicity.

Fátima has two sons and a daughter. As seen earlier, Fátima experiences pressure from the negative relationships she has with her siblings (they do not participate in their elderly mother's care as Fátima would expect). Fátima's 17-years-old daughter sympathizes with her mother in her indignation with the rest of her family, and she lives her mother's feelings as if they were her own.

> *My oldest daughter, who is 17, she does not tolerates my siblings, she does not stand them. I do not like her to have that resentment because it does not correspond, but she is aware of the conflict and supports me. Two years ago, my mom had high triglycerides, and was given a drug that makes her lose consciousness and everyone thought my mom was going to die. Then, from 'night to day' this house was full of people because my siblings all came at the same time to visit my mother. One day, my daughter, who at the time was 15 years old, began at one point shouting to my siblings and their families, she said: 'damn you all, get out of here, who do you think you are coming to this house now that my grandmother is dying, get out now, why don't you come when she's okay?!' And of course they [the siblings] think my daughter is also arrogant like me, but it's just that she feels the impotence of seeing me tired and all by myself in my mother's care. (Fátima)*

However, not all daughters understand their mother's involvement in their elderly grandparent's care nor do they sympathise with their mothers. According to some carers, their daughters disagreed with their high level of involvement in elderly care, claiming it affects the relationship between mother and daughter in a negative way. This arises when the carer mother refuses to support their daughters with their respective children's care. Daughters get mad because they expect their mothers to be available for their children's care support, resenting their relationship with the carer mother.

Josefina brings up the difference in the relationships with daughters as compared to sons. She has three sons, a daughter and six grandchildren, whom she doesn't see very often since she cares for her elderly parents. For Josefina, the relationship with her daughter is more delicate than that with her sons. It's not always neutral and there are conflicts once in a while because she is not visiting her granddaughters nor is she available to spend time with her daughter. Josefina's biggest respite is going to her beach house with her husband, ideally every possible weekend if one of her siblings assumes the elderly parent's care. The fact that she is not available either on weekdays or weekends is not welcomed by her daughter.

> *...My daughter gets angry sometimes... Sons ask for nothing (laughs), they are wonderful, with a soccer ball they can be happy; women are more demanding. (Josefina)*

Though some grandmother-carers of elderly parents agree to take responsibility for their grandchildren's care as well, not all grandmother-carers of elderly parents agree. When grandmother carers disagree, there is conflict with their daughters.

Although having a conflictive relationship with their daughters is not an ideal situation, caregivers who refuse to support their daughters with their children's care are convinced about the care work for the elderly parent, so are not much affected by this conflict with their daughters. They prefer their daughters understandood them, but in these cases, the deteriorated relationship with daughters is not a decisive factor in determining the intensity of the carer's experience.

Isabel, a 51-years-old carer, lives with her severely dependent father and her lowly dependent mother. Isabel lives with her daughter and granddaughter. She refuses to be her granddaughter's carer as well. Isabel won't budge even if her daughter is very angry with her. According to Isabel, she has already raised and cared for her daughter, her daughter should not continue to depend on her mother. Isabel thinks her role now is to be her parents' caregiver and when she has free time she prefers to spend it on leisure activities with her partner whom she recently met. She does not regret this attitude. On the contrary, she assumes her role as what should and needs to be done, no matter what her daughter thinks and feels.

> *...I am over 50 years old...I'm not like all grandmothers now that take care of their elderly parents and their grandchildren. I've done my work raising and now I'm in another stage, besides taking care of my parents I want to live and take advantage of the little free time I have left to enjoy my remaining years with good health. (Isabel)*

The majority of caregivers with grandchildren agree, however, to support their daughters with their own children's care. These grandmother carers would like to reverse the gender care-obligation they have lived and allow their daughters to free themselves of a caregiving life. This attitude also creates a closer relationship between mothers and daughters based on gender complicity. This gender complicity is part of a process towards greater gender equality. The mother-daughter complicity makes sense within the fight to validate themselves outside the family arena (Attias-Donut, Lapierr and Segalen 2002). This relationship based on complicity and support, gives carers a positive satisfaction independent of the workload and fatigue associated with caring for both an elderly and young children.

As is the case in this study, the relationship between adult women and their own mothers is perhaps the most complex and emotionally charged of all relationship within the family (Cohler and Grunebaum 1981). Women carers did not mention any strained relationship with their sons because of their role as elderly caregivers. It seems the elderly carer role is less compatible or causes more conflicts with the role of a daughter's mother or a grandmother of her daughter's children when compared to conflicts associated to the role of mother of a son or the grandmother of her sons' children. One reason for this could be that in a couple the expectation is that it is the woman's mother – not the man's mother – who provides care for the grandchildren. There may be different and less demanding expectations for the role of the grandmother from the male partner's side.

Carers are generally satisfied with their relationship with their sons. Any support sons provide with the elderly care, even if minimal, is highly appreciated by the caregiver. Both Lucy and Consuelo feel grateful by the support their sons give them with the elderly care, even though their involvement in care consists in sporadic support with tasks that require physical force or surveillance of the elderlies while main carers, their mothers, have to go out of the house for a while.

Relationship with the partner

Becoming the carer of an elderly parent or parent–in-law transforms the carer's relationship with his or her partner. Positively or negatively, there is a change, and the elderly care takes place in this context of relational change that alters carers' emotions. Carers have less or no time to spend with their partner. In many cases carers can no longer take vacations with their partners. If care takes place in a context of cohabitation, there are changes to household dynamics, infrastructure and finances. Any conflict with the carer's siblings invades conversations. In addition, the carer's physical and mental fatigue at the end of the day alters their intimate life.

How these changes affect the carer's relationship with their partners varies among cases. Some partners react positively and provide emotional support to their carer spouse; they encourage them to be patient and keep going with elderly care. Other partners remain outside the care situation and pay little attention to the caregiver in issues related to the elderly care. There is a third group of partners who complain because they would like things to be different regarding their spouse's involvement in elderly care. More often in this study, couples would not usually fall into strong fights as a result of a spouse caring for an elderly, even though in all cases the relationship changed.

Caregivers' experience of the changes to their relationship with their partners, and their partner's reaction, depends on how their expectations toward their partner's support matches their actual support. Reactions and experiences also depend on the couple's historical relationship, on how carers perceive the changes and on how they perceive their own role as carers.

The majority of carers in the sample do not expect their partners to help them providing care to the elderly. Carers do not expect partner's involvement even in the cases where the elderly in need of care is a parent-in-law. When women receive their partners' emotional support they greatly value it. If they don't receive it, they won't start a conflict because of it, and in most cases, they would accept the lack of support. Female caregivers do not interpret it as negative; they do not expect greater support from their partners.

In the context of married women in paid employment, Hochschild (1989) questions why men have not taken over some of women's responsibilities at home. In these situations, women's power in the family negotiations should increase, putting women in a better position to reduce their home responsibilities. Though their power increased, women did not even enter the negotiation, they did not ask their spouses to do more around the house. Men did not increase their responsibilities on their own either. Working women's attitudes towards their spouses may be rooted in love or in the effort required in current times to keep marriages together (Kremer 2007). In some of this study's cases, women who don't receive their husband's support, rationalise the lack of emotional support – or any other support thereof – as legitimate male-related behaviour.

Sara's husband calms her whenever she losses her patience with her elderly mother's care. Sara values that greatly, as well as her husband's kindness towards her mother. As a couple, they have lived with the elderly for five years. After a hospitalisation, Sara and her husband built a special room and bathroom for Sara's mother in their house. Her husband has never complained because of any care-related issue, although they have been major changes in their family dynamics and finances, and the fact that Sara's only brother does not provide any kind of support. On the contrary, her husband has always been very supportive. The minor disputes they have once in a while never scale up. Sara can get mad from the fact that no one understands her because no one spends the whole day with her elderly mother as she does. Sara's husband calms her down and convinces her that her mother has always been that way and that she needs to be patient. After these minor disputes, Sara is grateful of her husband's patience and kindness.

> *Uf, my husband is the opposite to me: I always accumulate anger against my mom, my husband, on the contrary, tells me that I have to be patient, that I already know how my mom is, that I have to be patient. He calms me. He is very nice with my mother, he is always asking her if she needs anything, he is like a son [to her]. Instead of him being bored and tired with the situation, he tells me I have to be patient, but it's me who spends the whole day with her, not him, it's too much weight for me. However, I appreciate his kindness, especially because it's my mom and not his, and she lives with us. (Sara)*

Pilar is also satisfied with her husband's attitude towards her role as her elderly father's main carer. He doesn't intervene too much. He basically has never complained about her involvement in the elderly care although she is fully dedicated to him. Pilar spends the whole day at her elderly father's house providing care; her father lives next door. She also sleeps, every other night, at her father's house. Her husband has always been supportive and nice to her. Pilar thinks that the fact that he is still working is of great help, because he works long hours so gets to their house to just eat and sleep.

> *Look, thank God my husband has been supportive and patient and very aware that I'm caring for my dad and he has never given me problems. Before, when my mother was alive and sick, my kids were still living with us and I was always coming and going from their houses to mine, and always worried about my own household tasks and family, but my husband has always accepted that I have to look after my parents and be with them. Thank God he is still working and there has been no problem. Since my dad fell and broke his hip I made the decision, with my sister, to stay every other night with him and my husband did not put any problem. (Pilar)*

As in various cases in this study (e.g. Pilar) and consistent with other research, married women caregivers or those living with a partner expect little from their partners. Carers see their husbands or partners as supportive so long as partners neither resent nor interfere with their caregiving activities (Abel 1989; Matthews and Rosner 1988).

Similar to Sara's case, Violeta's elderly mother moved in with her and her family when she started needing help. Violeta is aware of a change in the relationship with her husband, not necessarily a positive change because they have become, as she puts it, '*like friends*' and not a couple that shares intimacy. Violeta values her husband's emotional support and the patience he has with the care situation. His support comes despite the lack of time they can spend together and the bad humour she has. Violeta's caring role causes her a daily and heavy feeling of pressure; her husband is always providing her with emotional support and she appreciates it.

> *It [her role as her mother's carer] changed my whole life, everything. I kept working when she came to live with us and that was difficult, luckily at the end of that year I retired. Still, it changed my life. I'm running everywhere and I end up exhausted every night, and obviously that has affected my marriage, we don't have time for the two of us any more. At night we go to bed tired and we are like friends… (Violeta)*

Not all carers perceive their partners or husbands as nice and supportive. In some of the cases where husbands are mostly absent, what carers resent the most is not that their husbands do not support them, but the extreme loneliness in which they live. Despite this discontent, carers do not ask their husbands to be closer to them.

One of the reasons why male partners do not give emotional support to their wives is because their carer wives prefer not to share with them these issues under the argument that they wouldn't care or wouldn't understand. Carers like Victoria or Rita say their partners do not want to listen to stories about care. Rita spends the whole day alone in her house caring for her elderly mother with Alzheimer's disease. She lives with her husband, her daughter and son-in-law. They all work outside the house full time; Rita stays alone with the elderly mother and the dogs. She works hard solving her mother's demanding caring needs. The change in her and her mother's relationship and the loneliness she experiments daily makes her emotionally vulnerable. When her husband arrives home every night, Rita says nothing about her daily routine, about her feelings towards her caregiving role. For Rita, care is a female subject, and men get bored if they listen too much about care-related issues.

> *I never talk about it with my husband. He has his own problems and suddenly men get bored if one tells them about those things [care related things], they don't understand. (Rita)*

Victoria, the main carer of her mother-in-law, thinks like Rita. For her, her husband does not understand. She once tried to talk to him about her worries and feelings; she was tired and sad. Her husband reacted badly. He didn't understand and misinterpreted Victoria's feelings, proposing her instead to take the elderly to a nursing home if care causes her too many problems. Victoria was just trying to find relief and understanding after a hard day. She never tried to talk to her husband again when she is sad, tired or worried. She accepts his attitude because *"men do not want to hear about caring issues, they already carry their own problems"*.

For one group of women carers although their male partners provide them with emotional support, they have, once in a while, disputes that result from their role as main carer of their elderly parent. These disputes were not recurrent and never scaled up. For other caregivers, disputes with their partners where more common and negatively affect their relationship. In all these cases, conflicts originated in the fact that main carers carry with all the elderly care without receiving any support from the rest of the carer's siblings. Husbands get tired with the fact that none of their siblings-in-law contribute, they dislike that their wives carry with all the work. They complain and show discomfort with the situation. The carer often feels there is nothing they can do, that they won't abandon the elderly parent, and they cannot force their sibling to cooperate.

These disputes increase carers' pressure. How much the ressure will increase as a result from changes to the couple's relationship is determined by how the carer perceives her role as the elderly caregiver. Two cases, Claudia and Ofelia, show how this perception mediates the impact of the spousal relationship on carer's feeling of pressure.

Claudia has always had a positive relationship with her husband and now suffers the first disputes because of Claudia's high involvement in the elderly care compared to her siblings'. Her relationship is re-adjusting. Claudia is deeply convinced of her caring role. Her conviction allows her to better tolerate the disputes she now has with her husband.

Claudia is 60 years old; she is married and lives alone with her husband, they have two children who live independently. She works as a cleaner. She is her mother's main carer. Her mother has a recently developed low dependency level. Her mother lives alone in a different municipality, an hour and a half away from her place by public transportation. Her mother has been single for more than 30 years ago, when her couple, Claudia's father, abandoned her and their seven children. Claudia's mother can do most daily activities by herself. She needs help cleaning the house, taking some medicines, managing her money and visiting the doctor, among other similar tasks. Claudia visits her mother at least four times a week; she takes her to the doctor whenever necessary and goes to her mother's place again if her mother needs help. Claudia has always had a positive relationship with her husband, but lately they have had some disputes because, as she says, he claims she is too invested in her mother's care and that it's not fair because they are a phratry of seven, so Claudia shouldn't take the whole responsibility under her shoulders. Though there are disputes (they have never scaled up), Claudia does not want to reduce her investment in her mother's care. Care, for her, responds to the historical relationship she has had with her mother. It responds to the love she has for her mother. If her siblings do not cooperate more in the future, she will still care for her mother. She is willing to bring her live with them, even though it will take her spousal relationship some time to re-adapt to her new role.

> *Now, for example, my husband wants to take a leave from his job so that we can take vacations together to go to the South [of Chile], but how can I do it with my mom? That's when my husband gets angry. He says that I have more siblings who could care for her while we go for a while… Sometimes my mom makes me go late to her place, and my husband gets angry, he tells me that if I have more brothers why don't they go instead. Even in front of my children he complains 'that your mom spends too much energy and time with your grandmother and she is the only one among her siblings that cares'. And I tell him I'll care for her until her last day. (Claudia)*

On the contrary, Ofelia has become painfully distanced from her husband. Ofelia became her father's main carer because she was the one in the phratry that lived closest to him; she does not receive any support from her siblings. She would like things to be different, she would like to be less involved in her father's care but since no one else from the phratry gives support she feels she has no option. She does not find a solution and feels the pressure of elderly care and its consequences for her spousal relationship. She is 59 years old, her father is 89. During the day, Ofelia works as a teacher in a special needs school, a job she's had for 37 years. She and her husband have three children, the youngest daughter, school-aged, lives with them. She has the best recollection of their past family relationship and the good time they used to spend together, specially during the summer holidays when they travelled, camping, throughout the country. All of it is gone: no more vacations, no more leisure and quality time together. Ofelia's involvement in her father's care, added to her teaching job and household tasks have left her without time to spend with her husband. She regrets and suffers, she would like to be closer to her husband as they used to be, but the sum of her daily life responsibilities limits her. Above all, the distancing of her spousal relationship is what contributes the most to her daily life experience's intensity.

> *My husband complains. He says there is no reason for me to take the whole care responsibility on my own. He says I will have a stroke like my mom if I continue like this and that nobody is going to care for me, 'then they [Ofelia's siblings] are going to remember you exist'. In reality it has deeply affected my relationship with my husband, even my sex life because I go to bed late and super tired at 23h30, my husband is already asleep because he gets up early around 6h, even there it has affected our relationship, it is no longer as it was before, we are further away, distanced, that worries me too much. And we have not even had the time to sit down the two of us and talk about solutions. (Ofelia)*

As mentioned, the great majority of conflicts between carers' and their partners originate in the fact that the main carer is too invested in the carer role because there is no support from the phratry. Another source of conflict with partners related to the elderly care stems from the historic relationship between the partner and the elderly in need of care. Although found in only one case, Ana María's relationship with her partner was negatively affected by the relationship between her husband and Ana María's elderly mother. In all other cases the relationship between the elderly in need of care and the main carer's partner was described as positive. The fact that Ana María's husband does not have a good relationship with her elderly mother adds pressure to Ana María's life. The strained relationship between her husband and her mother has endured since Ana María got married, but it has never worried her as intensely as today. Ana María expects her husband to forgive her elderly mother from the attitudes she has had with him in the past. She expects her husband's heart to soften given that her mother won't live for too long. But he doesn't budge, and if affects her relationship with him today.

It is unclear what the situation is for male caregivers' and their relationships with their spouses. Pedro's wife's attitude and involvement exceeds Pedro's expectations. '*She is a queen'* he says, referring to the emotional support and direct care she provides Pedro and his elderly mother. This is the only case in the sample of a male main carer with a spouse. Mauricio and Rodrigo are the other male caregivers in the sample but they are single and widowed, respectively, so it is not possible to compare this experience to that of others.

Carers' engagement in the elderly care changes the relationship they hold with their partners. As in other relationships, these changes are not necessarily negative or positive; in the majority of the cases it doesn't bring about major disputes. Discussions commonly revolve around siblings' involvement in the care arrangement but do not escalate. In general, caregivers expect little from their partner regarding their support for elderly care. They value their partners' support, especially the fact that they do not resent or interfere with their caregiving activities. The fact that elderly care is considered a female issue by some carers, makes them not only expect little from their male partners, but also, isolate care altogether from the relationship they have with their male partners. In cases where husbands complain frequently (a complaint rooted in the fact that no other carer's sibling participate in the elderly care) and the spousal relationship becomes distanced, caregivers feelings towards these changes will depend on how they perceive themselves as caregivers, if, as Claudia, they are happy with their decision to be the main caregiver of the elderly, the transformation in the relationship with the partner are tolerated better. On the contrary, if the role as the main carer of the elderly is seen as something imposed and not chosen freely, as in the case of Ofelia, the distancing and complains characteristics of the relationship with her partner, will be add pressure to the caregiving experience.

7.2.5 Conclusions

The relationships a main carer keeps with their social environment are fundamental to understand their caring experience. The intensity of the care experience cannot be interpreted outside the social relationships in which care takes place. A positive relationship between the carer and both his or her siblings, the elder in need of care and his or her nuclear family is of pivotal importance to reduce the intensity of the care experience.

The onset of care and the dependency path change relationships with both the elder and siblings. In many cases, the care relation is an intensification of a pre-existing relation pattern; in other cases, care opens a new, not necessarily easy, relationship. The emotions that emerge from an intensified or recreated relationship are rooted in the history of the relationship. Adela appreciates her new relationship with her cognitively dependent mother because they always had a bad relationship in the past; the dependency path opened her an opportunity to have a positive relationship with her mother. Rita, also caring for a cognitively dependent mother, suffers with the new relationship; she would like to go back in time and bring back what they had before, a relationship of complicity and friendship where she plays the role of a daughter and her mother that of a supportive mother.

Relationships in the care context are not exclusively "good" or "bad". They have positive and negative aspects. The overall balance between the positives and negatives determines the quality of relationships and contributes to the carer's overall experience.

The positive and negative aspects are not unequivocal. A particular relationship may be positive for some carers but negative for others. The positive or negative aspects of a relationship result from the main carer's expectations towards others. Fátima, for example, has a negative relationship with her sisters that increase the intensity of her care experience. She is angry at them. She expects from her sisters a higher involvement in her mother's care, but that involvement does not exist. Other carers don't share these expectations and are content with sporadic support.

The relations carers hold with their social environment is key to understand the way they experience their daily life as carers. Relationships can make a very difficult caring situation to be experienced with positive feelings (e.g. Silvia). Relationships that give rise to conflict can make a comfortable care situation become one felt with strong pressure (e.g. Violeta).

7.3 The ideal care compared to the actual care situation

The ideas carers have of a ‘good caring’ situation is also related to the way they perceive their role and experience care. Carer’s aspirations towards an ideal care situation and how far their situation is from these ideals will shape their experience as emotions will result from the way actual care compares with their ideal of care. The carer’s perception towards their role will pose less pressure if their care ideal matches their actual care situation; carers who have care ideals that differ from their actual role in the elderly care will experience their role with greater pressure. For example, a main carer may find that the ideal care situation combines paid employment with the elderly care and delegation of part of the care duties on an external paid carer. This carer may, however and due to different circumstances, find it impossible to find paid work that would allow her to pay an external carer. This person will feel the pressure of not being able to engage in the elderly care as she would like (delegating some duties), and complete dedication to elderly care will make her uneasy.

A care ideal is a definition of care, an idea about who gives it, and how much of what kind of care is “good enough” (Hoschild 1995).[87] Care ideals are culturally shaped moral rules, embedded in societal structures that individuals follow to make their decisions in relation to others (Kremer 2007).[88] Most care ideals emerge through carers’ narrative of their situation and how they would like it to be. At the individual level, these ideals are revealed when carers explain the reasons why they have rejected other care possibilities for their elderlies. Care ideals also emerge when carers talk about how would they like or or would not like to be cared for when they become in need of care. By exploring the perception carers have towards their role and their ideal care situation, we have another clue to understand the intensity of their caring experiences. Ideals of care also offer hints on how the government can lessen the intensity of elderly carers’ everyday life.

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[87] Hochschild (1995) distinguishes between *traditional*, *postmodern*, *cold modern* and *warm modern* ideals of care.

[88] Care ideals have been used by Kremer (2007) to understand national variations in caring states. In reference to childcare ideals and across European countries there are four *ideals of care*: *inter-generational care* (grandmothers look after grandchildren), *surrogate mothers* (a paid non-professional minder imitates the role of a mother), *parental sharing* (fathers are expected to do more of the caring), and *professional caring*. Though a relevant concept to understand carers’ experience, it is unclear whether these four care ideals apply in the context of emerging economies and in the context of elderly care.

This section explores carers' care ideals and analyses their relationship with their own care experience. In interpreting carers' care ideals it is important to have in mind the Chilean context, the available care possibilities for different groups as well as the cultural norms as described in previous chapters. The fact that, for example, people from the most disadvantages socioeconomic group do not consider external support as an ideal care situation, might well be due to the historical absence of the State support in this domain, or by the fact that their economic means are not enough to pay an external caregiver, making external support an unthinkably option.

Indeed, in this study it is difficult to distinguish if carers' current care ideal is driven by the possibilities for elderly care or by cultural norms or both. It is thus unclear whether these ideals would change if they had different possibilities for elderly care. Where possible, socioeconomic contrasts allow distinguishing the two under the assumption that cultural norms are shared across socioeconomic groups. For example, most low-income household cases in this study find unthinkable to have their elderlies in a nursing home or cared for by an external paid caregiver. This could be the result of a cultural norm, but it could also be that the quality of the nursing homes available for low-income households is extremely low. Indeed, for high-income household carers, the option of a nursing home for their elderly parent or parent-in-law was not out of the question.

As described in carers' motivation to care, the normative component behind the carer role is strong in this study's cases. Some carers would like their investment in elderly care to be different but the pressure exerted by social norms coupled with the lack of alternatives to delegate care makes their care situation different from their ideals of care, increasing their dissatisfaction with their carer role.

Five different elderly care ideals are found in the study through the carers' narratives. They are strongly associated to carers' income level, with the relationship between the elderly and the carer as well as the motivations and circumstances by which the carer took up the role. These are:

- *Partly delegated care*, meaning that care is provided mainly by a family member (most likely a daughter) delegating some of the caring tasks to an external non-professional and paid caregiver so that the main carer can combine the carer role with other roles that contributes to self-fulfilment outside caring.
- *Full dedication to elderly care* in which a family member (usually a daughter, son or daughter-in-law) is fully dedicated to the elderly care because of internalised norms, reciprocity or the carer's interest to set an example for his or her future care. Under this ideal, appropriate care requires little or no support.

- *Siblings-shared care* in which members of a phratry participate in an egalitarian way in the care arrangement.
- *Full dedication as paid work,* in which carers accept full dedication to care if there is monetary compensation for the care work and the paid employment opportunity cost. Compensation can come from the government or the family.
- *Full delegation on professionals*, either through the elderly living in a nursing home or a situation in which the elderly remains in their home assisted by professionals.

The ideal of what appropriate care is contributes to understanding carers' experience when the ideal of care differs from or matches with their actual situation. Variation in care ideals also explains variation in the intensity of the care experience across socioeconomic status and gender.

7.3.1 Partly delegated care

Some – not all – caregivers would like to combine their caring role with other roles and activities by delegating some caring tasks. None of the low-income household carers in this study share this care ideal; it was only seen among middle- and high-income household carers. It was especially common among women who were in paid employment at some point in their lives.

Violeta, 62 years old and with a historically tense relationship with her elderly mother in need of care, is not happy being her mother's full-time carer without any form of respite. She feels a strong moral obligation to be her mother's carer because she is an only child and no one else is available. Violeta, as introduced earlier, worked her whole life and was looking forward to retirement to have free time and travel. She sees caring for her mother as an obstruction to her original plan. Ideally, Violeta would like to delegate care to an external caregiver for a few hours a day. Financial constraints limit her possibility to externalise care. This distance between her ideal of care and the current situation, together with the sum of bad relationships in the past imply that she does not have a positive experience of care. She struggles and assumes her role with pressure.

> *I would feel guilty leaving my mom in an elderly nursing home, I know they don't last long, they give elderlies their medicines and they die. The option of a good nursing home is too expensive, you have to pay more that 500 thousands pesos [a month, approximately 715 euros] plus all what you have to bring [medicines and some food]. I have a friend who works caring for elderlies in a nursing home and she told me that the cheapest room costs 300 thousands pesos [430 euros] and still they are better cared for by their families. What would be the ideal for me is to have a person that helps me caring for her a couple of hours a day, but it's also a very expensive option, they cost like 20 thousand pesos a day [30 euros], and the only thing they do is care for the*

> *elderly, and I would still have to do all the housework and prepare lunch for that person, and at the end it's very difficult to find a trustworthy person as well. (Violeta)*

Adela is 58 years old and comes from a middle-income household; she is in paid employment and is the main carer of her elderly mother. She delegates care on a paid caregiver, a male neighbour whom she trusts. Her mother's level of dependency has increased lately. Her ideal care is a day-care centre. Although Adela is satisfied with the current care arrangement, she fears that she will soon need another care arrangement because the paid carer, being a man, does not change her mother's diapers or give her a bath if she needs one. Adela fears that as her mother's condition deteriorates, her mother will become even more aggressive and difficult to care. Adela feels good with herself because she is doing the right thing, but her care ideal would be an arrangement that allows her to work and care at the same time. The idea of having to quit her job adds a small feeling of pressure to her experience. She thinks a day-care centre offers the perfect solution.[89]

> *I would like a place where I can bring my mother during the daytime, so I could go to work and leave her there every morning and then pick her up at nights, in the evenings after work. That's what I would like the most, I would be fine and she as well, because I imagine that she will be in a place with professional carers and they will have to feed her, clean her, everything. And then I take her home at nights ready for bed, hopefully with her bath already taken. (Adela)*

Colomba is 36 years old and is the main carer of her 84-year-old father who has a low level of dependency. She belongs to a high-income household and manages her father's medical appointments, takes him to the appointments and manages the house they share. A woman paid caregiver comes three days a week to help her with household chores. Colomba works as a landscape architect and loves her job, she is already saving money in case her father needs more hours of paid care so that she can continue working for pay. Her priority and her ideal of care is one in which her father's caring needs don't hinder her possibility to continue her paid job and develop her professional career.

7.3.2 Full dedication

Another ideal care situation for some carers is to offer full dedication to the elderly relative in need of care. This ideal is strongly crossed by income status. Some low-income carers, such as Silvia, do not even question their carer role. Silvia has a sister but she prefers her sister to keep the longest possible distance from her mother's care. Silvia's sister and mother have never gotten along and Silvia does not trust her sister in caring for her elderly mother. Silvia never thinks about combining caregiving with a paid job, although they live under a tight financial situation. Like Silvia, other non-working low-income carers feel their full-time dedication for

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[89] Interestingly, Adela talks about day-care centres as the perfect solution without knowing about the real existence of day care centres in Santiago (though few, they exist).

their elderly parent or parent-in-law is aligned to their motivation. They are either following strong social norms, doing what they should do, giving back to the elderly, doing it because of their love for the elderly, or because they expect their own daughters or sons to follow their example and care for them in the future. The care ideal for these carers is one of a fully dedicated adult.

This care ideal was mostly seen among low-income carers. For them, full dedication is practically the only possible care arrangement. Delegation on paid caregivers is financially impossible. Available nursing homes are perceived to be of bad quality and not even considered as an option. Financial constraints may determine this care ideal as a form of rationalisation of the lack of alternative care arrangement. However, this care ideal is also present among low-income carers who have the possibility to share among siblings. Even if a sister could potentially take part in the arrangement or siblings could contribute financially for the externalisation of care, some low-income carers have an ideal of care of a fully dedicated daughter. In these cases, the relationship that carers had in the past, or currently have, with the elderly they care is an important determinant of this ideal.

Silvia, Carmen, María and Sandra, all from low and low-middle income households, care for their respective mothers or fathers with moderate or severe dependency. Each of them said that if they could pay someone to help them with care duties they wouldn't do it. They prefer to be their own parent's caregivers. The argument given in these cases was lack of trust, not lack of monetary resources to pay an external carer. At least in their narrative, lack of financial means was not a reason to exclude the possibility of delegating care on an external paid caregiver. These carers think that the role corresponds to them and no one else could do the care work as well as they do.

> *I don't pay to anyone to help me, and even if I had the financial support from my siblings to do it I wouldn't do it because I wouldn't trust an external carer (Sandra).*

All carers who share this ideal care situation find that the most appropriate care that their elderlies in need of care should receive is one coming from the exclusive dedication of a daughter, they also think that the best care they could receive in the future is that coming from their own daughters

> *I would obviously like to be cared by any of my daughters, I pray God for not ending in a nursing home. (Sandra)*
>
> *I hope that my daughter will care for me in the future, that she will act by what she saw on me, that I didn't left my parents alone. (Eugenia)*

It is unclear, however, whether carers under this ideal would shift their position if monetary compensation for their work was available. It is possible they have not considered monetary compensation as a possibility in their care ideals and would adopt it if it entered their realm of possibilities. It is possible, however, that they do not accept pay for their work given the potential conflict with siblings that monetary compensation would bring.

7.3.3 Fully dedicated care as paid work

Some carers find that ideal care is one that is visible, recognised and paid as labour, either by the government or by the family. Care workthat is visible and recognised is one that is monetarily compensated. For Lucía, this compensation could have the form of a public salary or subsidy. For Ana María, it could be a salary provided by siblings who are less involved in the elderly care. For Mauricio it could be pension contributions for the time spent caring, in addition to a more generous social protection for those entirely dedicated to elderly care.

Both Ana María and Lucía, from practically opposite socioeconomic backgrounds, consider receiving monetary compensation for care work as an ideal care situation. Lucía, from a low-middle income household, is the main carer of her elderly father. She is a single mother of three children and runs with the financial expenses of her father's care by herself. None of her five siblings cooperate and her father's pension is spent in covering one of his grandchildren's tuition (as described earlier, one of Lucía's brother's was sued by his ex-wife because he abandoned their children; since the man does not have the money to pay for the tuition of his children, it is the grandfather—Lucía's dad—who must, by law, pay for it). Lucía has to work – and does work – to keep the household running and her father and children fed. Her ideal of care is not one of combining a paid activity with care work. She would, instead, like to receive a monetary compensation from the government for her care work. This would allow her to avoid the monthly economic constraints and would be able to stay at home caring for her father. For Lucía, the care she provides to her father is a job and one that should be compensated.

> *Look, I would like to have like a sort of pension so I can be dedicated to my dad's care, I would like my dad's care to be a way to earn my bread, and not to have fewer economic resources. My dad's pension is barely enough to feed him, and I, cleaning and ironing for other people I can barely pay the bills, electricity is expensive, I pay like 60,000 pesos [on bills, approximately 85 euros] and it is the same amount I earn cleaning one house a month. Then what I get cleaning the other apartment I use it to pay the water bill, so I really need to do miracles every month to eat, and if my dad is sick and I have to take him to the hospital or the primary health centre I have to figure out how to pay a taxi because I cannot take him in public transportation because my dad doesn't walk much and I don't have the physical strength to support him. (Lucía)*

Ana María, from an upper-income household, although not facing financial constraints, would like to be recognised by her siblings for the care work she does and would like to receive a monetary compensation from them. Ana María's mother lives in a high quality and expensive nursing home. After an adjustment period to get accustomed to the fact that her elderly mother lives in a nursing home, Ana María is comfortable with this care arrangement. The only missing point is not being compensated for her role as the main carer of her elderly mother.

Mauricio, 54 years old, had to stop working to be fully dedicated to his mother's and sister's care. He comes from a low-income household and experiences strong financial constraints. Being unemployed and out of the labour market he is not saving for a retirement pension. His lack of earnings does not allow him to visit a dentist to get his falling teeth fixed (dental health care is not part of the public health system in Chile and is very expensive for the majority of the population). For Mauricio, like Lucía, the ideal care would be one that is visible by the government and is compensated in some way.

> *We [carers] are invisible. You know, people take care of the sick people but not of the family carers... this is an invisible world. Well, it depends on the kind of carer because there are also those that are paid to take care of others and that's different. There should be a law that cares for the carers, the work should be recognized, but we do not exist. For example, between my age and retirement age I do not exist [for social protection purposes], I am not, I don't have the right to get sick, I am losing my teeth because I no longer have the money to go to the dentist, and if I ever need to go to the doctor for something more serious, I have to run there and ask to be seen fast, my mom does not have urinary holding so I cannot be out of the house for longer than 2 hours. (Mauricio)*

Other than Lucía or Mauricio, no other caregiver experiencing strong financial constraints suggested that compensation would be appropriate for the care work they do. Most carers with financial constraints express anger and worry when referring to the fact that elderly pensions do not cover the elderly's needs, or anger and sadness when they say their siblings do not contribute financially. Most carers with financial constraints did not mention the fact that they are not compensated or did not show any negative emotions because of not receiving money for their care work. Other than Lucía and Ana María who would like direct monetary compensation, Fátima, from a middle-income household, mentions that as a carer she has even less money given that she cannot work and her siblings should be aware of her opportunity cost. However, like all the other caregivers, Fátima does not make a claim for monetary compensation for her care work.

Receiving monetary compensation for the care work – and the recognition of care as work it entails – is not a popular care ideal in this study's sample, even though the opportunity costs and long-term consequences of being fully dedicated to elderly care can have profound financial implications. There is a strong cultural component to the non-recognition of care as work. It has recently driven policy makers and other stakeholders to recognise that care work should be valued in all its dimensions and should be addressed by the government with a focus placed on shared social and family responsibility (Comunidad Mujer 2014).

Among the few carers who share this ideal for recognition and compensation, those from low-income households expect it to come from the government (e.g. Lucía or Mauricio). For high-income household carers, like Ana María, recognition and compensation is expected from siblings. For Ana María, ideal care is one that is solved by private means; for Mauricio and Lucía it has a public component. These expectations regarding public or private contributions for care are in line with the current public policy scenario in Chile. As described in a previous chapter, access to public support in Chile is non-universal (except from health care and primary and secondary education) and is focalized on individuals and households in most need of support. Lucía and Mauricio, like other people under social and economic vulnerability, know that the government is and should be a channel for support, while high-income individuals do not expect such a role by the government in their own care needs because they are used to solving their needs privately.

7.3.4 Shared care among sisters or sisters-in-law

Other caregivers express that the ideal care for their elderly parent or parent-in-law is one where care tasks are shared among sisters or sisters-in-law. This arrangement would allow carers to have respite from caring tasks while continuing to provide care for the elderly parent. Care would take place in a more egalitarian care arrangement among the females of the phratry. This care ideal was seen across carers from different socioeconomic background, among carers' whose main role was that of a care manager as well as among those who do not delegate any caring task and provide all caring activities. No low-income household carer mentions this ideal of care.

Consuelo is the main carer of both her parents-in-law with whom she lives. She became the main carer because since she married she always lived with her in-laws. Her husband has two other sisters who live close to the elderlies but do not participate in the care arrangement. Consuelo's main role in care is managing care; direct care is provided by an external caregiver on weekdays and by Consuelo with the support of her nuclear family on weekends. For her, an ideal care for her elderly parents-in-law would be one with equal participation of her siblings-in-law.

> *The ideal care for my parents–in-law is that everyone [the siblings-in-law] assumes their role as caregivers and not just me and my family, that they do not rest exclusively on me just because I live with the elderlies. (Consuelo)*

Trinidad has a similar care ideal. Trinidad is the main carer of her elderly mother and brother. For her, the appropriate care would be one equally shared among siblings. Trinidad sued her sisters for not providing support for elderly care. She brought her care ideal to court, even though there is no law that states that elderly care should be shared among siblings.

Fátima would like to have paid work, work that is different from her mother's care. She finds it unfair to stay home caring for her mother, while the rest of her siblings continue with their lives and professional development without caring about her mother. The ideal care for her elderly mother would be to count on her siblings' support. She would like to continue living with her mother and being her main carer but with the active participation of all siblings.

> *Oh... an ideal situation would be to count with the empathy of my siblings. That's what I'd like, that they be more empathetic with me and participate in my mom's care, that they come to clean her room, wash her clothes, stay with her occasionally, come to bathe her on weekdays and stay with her during weekends. That. Nothing more than that, the rest I can do it, after all she is my mom and I love her. (Fátima)*

Fátima experiences the moral obligation to care with pressure as it hinders her possibility to invest in her own projects. If her siblings were equally involved in her mother's care she would be able to develop other aspects of her life.

7.3.5 Full delegation on professionals

Many carers think about care provided by professionals in a nursing home or in their own home with professional assistance for the care they would like to receive in the future. This image is common even though they reject this ideal for the elderlies to whom they provide care today. Except in two cases, all carers who share this ideal have their elderly parents or parents-in-law living with them and it is the carers themselves who provide direct care. Only Ana María and Cintia have their respective mother and mother-in-law in a nursing home. Carers with this ideal of care for themselves but with a different care arrangement for their elderly parents now explain this mismatch on the fact that the elderly parent or parent-in-law expressed his or her desire for not living in a nursing home. A generational difference explains this mismatch among carers of all ages from upper-income households. Elderlies today assume that elderlies stay at their own place until they die and the family is the main care provider. Newer generations – the generation of today's carers – are open to other care arrangements that will free families, especially women, from assuming the whole of care responsibilities.

All carers sharing a professional-based care ideal for their future care come from high and high-middle income households. The only exception is Cintia, a low-middle-income caregiver who has her mother-in-law in a nursing home and previously had her mother in the same nursing home.

Marita, from a high-income household, is her elderly mother's main carer. She delegates some caring activities on an external paid caregiver, a Peruvian migrant. Marita and her mother have always had a positive relationship between them. For her, elderly care is not experienced with a high level of pressure, but, when thinking about the most appropriate care, she says the ideal is care by professionals in a nursing house.

> *Look, I am inclined to live in a nursing home, I wouldn't have any problem with that, with being surrounded by elderlies that talk about the same issues every day because they forget what they have talked about the previous day. But my mom, she is from a different generation. She always stated her preferences related to her care so that's why she is not in a nursing home but living with me, we actually never thought about that possibility, which doesn't mean that I don't find it the best solution for my own care. (Marita)*

Consuelo's ideal care for her elderly parents-in-law, as already seen, is to count on her siblings-in-law's support while the elderlies stay at their own place and also receive the support of an external paid caregiver. Although many people have suggested the option, she doesn't think about moving the elderly couple to a nursing home. Her father-in-law is still with intact cognitive capacity and he has always expressed his desire to stay in his own home until his death. However, when thinking about her own care when she becomes an elderly, Consuelo finds ideal the care provided in a nursing home because she doesn't want to bother anyone.

> *I don't want to be a burden. I tell my children to please don't make a problem out of my care, that they can leave me wherever they want because I don't want them to live bad moments or bad experiences, nor I want one having to be more engaged in care than the others. The easiest is that they leave me in a place, like the one they have in my school for the elderly alumni, I tell them to leave me there and that I will pay for it with my retirement pension. I have worked my entire life so at least I will have the money to pay for it. (Consuelo)*

Josefina's parents live in their own place and receive constant care from professional caregivers and a maid. Josefina's parents have a financial situation that allows them to afford this arrangement. For Josefina, the most difficult part of her role as main carer, apart from seeing her parents' health deteriorating, is the management of the paid caregivers. For her, ideal care is in a nursing home. She has been able to see the difference between her parents who are cared for in their own place with her mother-in-law's experience, who spent her last years in a nursing home. For Josefina, the difference for the elderlies is important, as is the difference for the main family carer. Josefina would like to spend her own last years in a nursing home, and she has been explicit about it with her daughter.

> *My mother-in-law was in the German Nursing Home, and I was completely in charge when my sister-in-law died. I had a very beautiful experience, I saw a woman that was very happy in the end of her life, and I was able to witness it… The thing is that all this goes by too fast [the elderly parent needing care] so you don't even have the chance to discuss it, but I think that my mom would have been a much happier woman living in that place, and my dad for sure because he is a social man, he likes to watch people. And the German Nursing House is very well thought out, there is an open cafeteria so there are always external visitors and you feel like you're free there, you don't feel locked in a nursing home, but in a five star hotel, full of sunlight and gardens… My parents would be happy living there, to the point that I have told my daughter, who is the only woman [among my children], that she shouldn't doubt if I ever I need help that*

> *she puts me there, I know I will be happy there and I will make the rest of my family happy, especially after experiencing my parents' care. I cannot compare my experience with my mother-in-law and the one I've had with my parents; [caring for my parents] has been three extremely heavy years for me, for all my siblings, in terms of our parents' care. I tell you that for a family to care for the elderlies they should think about it really carefully before taking on that role. (Josefina)*

But not all carers have professional care as an ideal. In this sample, it is more common to refuse a nursing home as an ideal for care, especially among carers from lower socioeconomic status who do not see a high quality nursing home as a possibility for them. Yet, as mentioned above, financial constraints are rarely the first argument for refusing nursing homes as an ideal for elderly care; strong social norms pointing towards care as an obligation for family members are prevalent as well. Low-income carers tend to refuse nursing homes on the basis that they have a bad reputation and quality and that they will feel guilty if the elderly is left in a nursing home. In a related manner, the refusal to rely on a nursing home is rooted on the elderly's common preference not to live in one.

Violeta would feel guilty for taking her mother to a nursing home. It is her role to care for her mother. She believes that elderlies don't live long in nursing homes because they receive a very low quality of care. Although she experiences her carer role as with high pressure, leaving her mother in a nursing home would replace the intensity of direct care with guilt, not necessarily reducing the intensity of her experience. Violeta's ideal care is that of partly delegated care, as seen earlier.

> *It doesn't go with me to leave her in a nursing home, she would go [die] in a 'one, two and three', also, she told me that she would never live in there and I would have a bad conscience leaving her in a nursing home. I know they don't last long there, they give them drugs and the elderlies die. And to be able to afford a good quality nursing home you need to pay more than 500,000 pesos [715 euros] plus all what you need to bring there, and we don't have that money, and even if we did have that money it would be better spent in the house. (Violeta)*

Violeta doesn't want to live in a nursing home herself when she becomes dependent either. She is afraid of her future as an elderly in need of care.

> *I ask myself what will happen to me in the future, maybe they will throw me in a nursing home, my husband promised me that it won't be like that, but you never know with my son and his wife. (Violeta)*

Many carers think leaving an elderly in a nursing home is a form of abandonment. Violeta speaks of "throwing", "leaving" and "abandoning" the elderly when she refers to the possibility of a nursing home as a care arrangement. Eugenia is explicit in explaining why she thinks leaving an elderly in a nursing home is abandoning him or her.

> *Nursing homes are tough, they are tough because there is too much abandonment of the elderlies by their families, abandoning an elderly is tough because you think that they have had lots of kids and then they end up in that place abandoned. (Violeta)*

Pedro struggles with his mother’s care. The hardest for him is seeing her mother’s health deteriorate and having lost the relationship they had before. He also struggles because he no longer has time for himself; after retiring from paid employment he became fully dedicated to his mother’s care. He is aware that changing the current care arrangement will not reduce the intensity of his experience. His care ideal is far from that of a nursing home. He has never even considered it. He thinks that that’s what children are here for, to care for their parents when they are old. Pedro does not root his rejection of a nursing home in monetary constraints, but in children’s moral obligation to provide care to their elderly parents.

> *I would never, never put my mom in a nursing home, children, we are for that [for caring for the elderly parents]. No, no and no, never. When my mom was at the hospital I always left worried thinking about the care she received there. With my sisters we have never thought about that option. Just like we now pay a trustworthy woman to care for her during the day, we could also pay to have her in a nursing home but we will never do that, we are not taking her out of her place or from my dad’s side. (Pedro)*

Estela refuses the ideal of a nursing home for her mother’s care and for her own future care because of their bad reputation. She is an only child and a middle-income carer. She has been caring for her mother for the last fifteen years. They have always have a good relationship. She worked as a teacher for 33 years, and her retirement coincided with the period in which her mother started needing more help with daily activities. She refuses the idea of a nursing for her elderly mother care because she has heard of a very bad experiences from a neighbour whose mother is in a nursing home. The neighbour decided to take her out of the nursing home because she was almost dying due to the bad quality of the care she was receiving.

> *I would never leave my mom in a nursing home, never. A friend of mine has her mother there and she took her in miserable conditions, full of bruises and extremely thin. I will never do that. (Estela)*

Estela is single and does not have any children; her future care is a subject that causes her anxiety. She fears ending in a nursing home. In her future as an elder, she would like to be in her own place cared for by a paid but trustworthy caregiver. She still fears being mistreated by an external carer.

> *I don’t want to live until I have to depend on others. I would like to live until I can be autonomous. I am awfully afraid of being elderly, it is really something that I fear a lot, I am afraid of ending up alone in a nursing home being badly cared and lonely, I am too afraid of that. The best option is maybe for me to stay here or in a smaller apartment and pay someone to care for me, but in that case I am afraid of mistreatment and abuse. (Estela)*

Carmen is the main carer of her severely dependent mother. Carmen comes from a low middle-income household and decided to stop working to be fully dedicated to her mother's care. She would never choose a nursing home as an appropriate form of care for her mother. She believes they mistreat the elderly. Also, her family does not have the money to pay for a high quality nursing home.

> *We never though about the possibility of leaving her in a nursing home, not even to pay someone to care for her. I feel sad thinking on elderly mistreatment. I decided to become her caregiver, to quit my job, just like that. I decided to stay with her because when I was working I was always nervous because she used to feel down, and one day she broke her hip, so it was too much to worry about. (Carmen)*

Silvia has no children and thanks God about it. She thinks it was meant to be like that so she, and only she, could care for her mother. She has never thought of the option of a nursing home for her mother. She thinks elderlies are very badly cared for there. She thinks it is her mission on Earth to be her mother's caregiver.

> *I think it was God's plan that I never have children so I can care for my mom. Maybe that was my mission here. Imagine if I had put her in a nursing home, she wouldn't last a month, not even a week. You know that they die in nursing homes because they don't receive the care they need, and they have many elderlies so they cannot be worried about the needs of each one of them, I have my mom already five years with me, because I am 100% dedicated to her. First it is her, second it is her, and then the rest, and my husband knows that. (Silvia)*

7.3.6 Conclusions

There is no unique care ideal in this study's cases. They vary according to carer's socioeconomic status. Different norms of obligation related to the elderly care and the different possibilities of care according to the financial means and government support shape care ideals. Care ideals are morally oriented, shaped by cultural norms and embedded in societal structures such as the welfare state (Kremer 2007). In Chile, this means that care ideals rely heavily on the family, particularly on women, and on the market, which gives access to care services only to those with economic means. Embedded in a particular context, individual carers may have one or another care ideal. Most low-income cases in this study find it unthinkable to have their elderlies in a nursing home or cared for by an external paid caregiver, even if on a part-time basis. These carers allude to a moral duty to care for their parents, but we must not forget the poor quality and bad reputation of the nursing homes available for those who belong to the lowest economic status. Indeed, for high-income household carers, the option of a nursing home for their elderly parent or parent-in-law or for their own care in the future was not out of the question as it was for lower-income carers.

Five different elderly care ideal situations are found in the study; *partly delegated care*, *full dedication to elderly, siblings-shared care*, *full dedication as paid work,* and *full delegation on professionals*. When the ideal of care matches the care situation there is no added feeling of pressure; when the ideal of care is very different from the actual situation, it can contribute to carers' intensity of care.

The four care ideals that do not imply a full dedication to the elderly, such as *professional care* or *partly delegated care* coincide with carers wanting to satisfy their own individual interests (other than providing elderly care) while remaining the main carers of elderly. These cases match carers' with an individualistic orientation (Pyke and Bengstone 1996; Guberman et al 2012). Individualistic oriented carers will see a conflict between their own interests and ideal care situation and their actual context and elderly care situation if they are not able to delegate caring. *Full dedication* to elderly care coincides with more collectivist-oriented carers (Pyke and Bengstone 1996). For them, exclusive dedication to parents' care is the most appropriate care. *Full dedication* meets their emotional needs and fulfils them.

Carers who have *partly delegated care* as an ideal care situation and can delegate care on paid non-professional carers contributes to a more positive care experience. The mismatch for carers who share this ideal but cannot delegate contribute negatively to the care experience, adding pressure. An ideal of care that is far from the actual care rendered to the elderly adds pressure to caregivers' experience.

Care ideals are related to how carers experience their role. Though it may appear that for some caregivers their care ideal may be a rationalisation of their situation, as is the case of low-income caregivers who have an ideal of full dedication to the elderly, these care ideals are also shaped by social and cultural norms. Care ideals also respond to generational shifts: older generations tend to refuse nursing homes and professional care, but younger generations are more open to this idea to free their children of any burden.

It is telling of the precarious options available to the elderly and caregivers, that single, non-high-income and childless caregivers have trouble thinking on a care ideal for their own care in the future. These cases prefer, above all, to die before needing care. They are afraid of the lack of satisfactory care possibilities for their future. Not having a spouse or children and not having money to guarantee good quality professional care leaves them without access to a desirable care situation. It is also telling of the intensity of the care experience that some caregivers prefer death over needing care. These are caregivers whose experience of caring for their elderly parent or parent-in-law is emotionally too sad to bear.

Carers who lack an ideal of care experience care even more intensely because their everyday activities remind them that they will be in an uncertain and undesirable situation in the future.

Where is government protection in these cases? Shouldn’t the government assume the role of guarantor of decent care for all its citizens? It is true, as described in the previous chapters of this thesis that the Chilean government has made progress in supporting elderly care, but at the level of individual experience, these efforts are hard to appreciate. It is unethical that a human prefers death before being in a situation of needing care, particularly when it is a human being that has provided care during her life.

7.4 Conclusions

Care is a multidimensional and complex concept. The experience of care is complex. Understanding the care experience requires dealing with this complexity. Care is more than the sum of tasks involved. It is more than the sum of tasks in a context of more or less difficult situations. Care is lived socially and emotionally; it is embedded in a structure of societal norms of what care is and should be and is embedded in a history of changing relationships.

Being the main carer of an elderly parent or parent-in-law is not easy for any of the cases of the study. It involves constant work, attention and disposition. It usually involves sacrificing personal life and projects. Care sometimes takes place in contexts of financial difficulties, deteriorated carer health, advanced carer age, multiple caring demands, combination with paid employment, high level of elder dependency and lack of formal and informal support. Yet facing daily difficulties like these does not necessarily mean that caring for an elderly parent or parent-in-law is experienced in an intensely negative way.

Despite the presence of objective difficulties, caring can be a positive experience. Despite the absence of difficulties, it could be an intense experience. Difficult situations do not automatically translate into pressure to caregivers' experiences. Although these situations explain a part of carers' experience they do not fully explain carers' daily intensity.

Higher levels of difficulties, such as those faced by Silvia, did not bring about a higher intensity of her care experience. Violeta's situation shows fewer difficulties when compared to Silvia, but her care experience is felt with more pressure, making it intense and unbearable.

The emotional dimension of care allows understanding how situations and difficulties translate into daily pressures, or not. Taking into account Silvia and Violeta's – and any other carer thereof – broader and deeper context unravels their care experience. It includes accounting for their historical and current relationship with their elderly parents or parents-in-law, the importance they accord to the social support they receive (or don't receive) and the relationship with other members of their family, their perceptions towards their role as carer and the reasons why they take on that role as well as their care ideal situations.

An important part of the intensity of the care experience emerges from caring work's relational component. Understanding the intensity of care requires acknowledging that care is more than work, it is work embedded in a deeply emotional and relational context. The relations carers hold with their social environment – in the context of their historical relationship – are key to understand how carers experience their daily life as carers. Relationships can make a very difficult caring situation to be experienced with positive feelings. Relationships that give rise to conflict can make a seemingly comfortable care situation become unbearable.

The experience of care is also shaped, to a lesser extent, by carer's motivations and reasons to assume the role and their care ideals, also rooted in social relationships and with an important emotional component. Carers who assumed the role voluntarily experience less pressure than those who feel they assumed their role by obligation. Carers' whose situation is far away from their ideal care situation also experience greater pressure in their daily life as carers.

Formal support can help reduce the intensity of care. Though the offer of formal support for elderly care is weak in Chile, participation in these programmes and their presence is valued by the recognition it entails (less so by the actual support offered). The programmes' ability to reduce the intensity of care is related to the perceptions they have towards their role as carers, how care must be rendered and by whom. Informal support from siblings can reduce the intensity of care if aligned to carers' expectations regarding siblings' involvement in the care arrangement. Neighbours and religious communities are important sources of support for main caregivers. Partners are not expected to provide strong support with the elderly care. More often in this study, conflict does not arise within a couple as a result of a spouse caring for an elderly, even though in all cases the spousal relationship changed as a result of care.

Care is a female issue. On the rare occasion men become carers it is because there are no female options available to adopt the caring role. Sisters and sisters-in-law, not brothers or brothers-in-law, are expected to provide support to the main carer. When the females of the phratry are not involved or are not involved to the level expected by the main carer, conflictive relationships arise. The men in the phratry are not expected to be involved; when they are, their participation is valued. When the main carer is a man, he tends to receive provide strong support.

Carers from more disadvantaged socioeconomic groups experience higher financial constraints. They are less motivated to combine a paid employment with care work and to delegate part of the caring responsibilities. Low and low-middle income carers provide more hours of care work and spend more time with the elderly in need of care. However, they do not necessarily have a more intense care experience as compared to those with a better economic situation. Higher-income carers are often more individualistic-oriented as compared to carers from lower income households. Caring hinders the accomplishment of higher income carers' personal interests, which go beyond the provision of elderly care. As with the interpretation of any other contextual variable of the care experience, the perceptions towards the carer's role, the motivations and reasons to provide it and especially the relationships in which care is embedded shape the emotional component necessary to understand how caregivers experience care.

General conclusions

Bernardita chose not to get married so she could provide care to her elderly father who needs help carrying out daily tasks. It is a job that requires her constant attention and that has defined her current life and her future family. She does not regret choosing celibacy for care, though every once in a while she looks at her married sisters and thinks about how different her life would have been with a family of her own, with a husband and children.

Fátima would like to have a job and take vacations with her husband and children, but she cannot as she is responsible for her elderly mother's care. Fátima finds her situation unfair but she has no support, she has no choice.

Mauricio, a single man, is the main carer of his mother and sister, both of whom have physical disability. No one else was available to take the responsibility of his mother and sister's care; he stopped working and stopped receiving income to care. His neighbours help, they are an important source of support.

Elisa always new that she would become her mother-in-law's carer as her husband is an only child. She combines her role of a mother of seven children (all under 18) with the care she provides to her elderly mother-in-law which does not cause major pressures in her daily life. She goes daily to church to get motivation and spiritual support.

Blanca is the main carer of her 102 year-old mother. Blanca is 78 years old herself. She has advanced osteoarthritis; she is extremely tired and in physical pain.

Andrea is the main carer of both her mother and aunt-in-law, both of whom have been diagnosed with Alzheimer's disease. She is also the main carer for of her granddaughter so that her 17 year-old daughter can finish school and have a better future than hers.

Violeta struggles with her role as caregiver of her elderly mother. They always had a difficult relationship. Violeta had been looking forward to her retirement so she could travel around the world. But now she has to provide care to her mother, causing her an intense day-to-day life.

> Silvia wakes up early in the morning. By the end of the day she is exhausted and lacks the energy to put on her pyjamas or get under the bed sheets. Caring for her mother takes all she has, but the love and appreciation she has for her mother makes her experience care as something emotionally rewarding.

Ofelia is a special education teacher for deaf children. She also provides care to her elderly widowed father. Handling both responsibilities, in addition to taking care of domestic tasks leaves her too tired; she wants to stop working. But she needs her salary. Her husband complains about her load and wants her siblings to participate in the caring arrangement.

> Ana María's mother is in an expensive nursing home, it was a difficult decision for her and her siblings to take her there. Her mother's care management is only her responsibility – she has a sister living abroad and two brothers living in the countryside. She visits her mother every other day, sets appointments with doctors and maintains contact with the nursing home staff, among other management tasks. She also helps her daughters with their own children's afterschool care and cares for them when they are sick. She does not want her daughters to interrupt their professional carers. She wants for them a life with more opportunities than the ones she had.

The complex experiences of these ten persons reflect those of informal, unpaid family caregivers. People like these care nine out of every ten elderly in need of care for. They come from different socioeconomic backgrounds; they have different ages and family structures. The great majority are women. They work hard, most of them for long hours. They give company to the elderly, change their diapers, cook for them, help them get dressed, arrange their health appointments, etc. They have to be available at all times if something happens. Even if not actively engaged, they still care. Care, for the majority of caregivers, is a 24/7 activity. It comprises direct care tasks and indirect care. The intensity with which care provision is experienced does not relate much to the amount of time spent in direct care.

Some carry all the tasks by themselves, sometimes in difficult health or economic circumstances. Some receive support from their siblings, a few are able to pay for external care and another few may receive some (very little) help from the municipality if they are poor and live in a municipality offering the services. Some live with the elderly, others do not; some have siblings, others are a single child; some have multiple caring demands, others only focus on the elderly. The circumstances under which care takes place is different from one carer to another.

They all share two fundamental facts, however: they work hard to provide care and they all expressed vivid emotions when talking about their experience. Some feel happy and fortunate to be able to care for their parents, others find the situation unfair and want everything to be different but have no choice.

This study uncovered these largely invisible experiences, showing that they take place in a context of a relative absence of public policies to support the provision of elderly care. Despite recent public policy efforts, most care for the elderly is currently provided by informal family caregivers with important implications in terms of inequalities. Up until now, there was a lack of knowledge regarding the experience of family caregivers and a disconnection between their experience and the emerging policy context. This research fills this gap by shedding light on the experience of care and mapping the policy development in the area.

This study thus answered questions pertaining to the macro- and micro-levels of care: What are the characteristics of the elderly care phenomenon in Chile? Who assumes the social responsibility for care? Is there a care crisis? What is its nature? What is the role of the government in Chile's elderly care regime, how has it evolved and what challenges does it face? Within the households where care is provided, who and under what conditions and situations does the job of caring for the elderly? What determines the intensity of the care experience? The answers to these questions can then help answer a final one: How can the role of the government adapt to the caregivers experiences and demands?

The understanding of the elderly care phenomenon through a micro and macro-level perspective illuminates the path towards a more equitable distribution of elderly care, one where the role of the government and different societal actors suits the experiences and demands of those who provide care to the elderly.

In terms of the social distribution of care in Chile, this study highlights the excessive weight and responsibility of families (and mostly women therein) in the elderly care. By relying on families to bear the social risk of elderly care – and on women within the families –, the unsupported familialism regime of elderly care in Chile maintains socioeconomic and gender inequalities. Results show the current (slow) policy development to redistribute care more equitably, highlighting the advances and remaining challenges to achieve an equitable social distribution of the elderly care responsibility among the Chilean society actors.

Some authors have claimed that Chile is experiencing, or will soon experience a care crisis (e.g. Arriagada 2010, 2013 and Acosta 2013, 2015). The changes in family structure, population aging and women's increasing entry into the labour force will produce a mismatch between the supply and demand for care. The evidence presented in this study supports this, but goes further: the care crisis in Chile is about a distribution of a social risk that lies almost exclusively on families and women therein. The care crisis as previously discussed is about a future where fewer female children will be available to care for their parents. The existing crisis, however, is one that does not question this social distribution of care. This study shows that the current distribution of care leads to daily intense care experiences for the people who, many times involuntarily, adopt the responsibility for elderly care.

The results of this study also contribute to understand the experiences of those who provide care to the Chilean elderlies. It adds to the existing knowledge on the intensity of the care experience, often studied through a quantitative (and limited) perspective. The thesis shows that the intensity of the experiences responds to the tasks implied in care work, to the different situations in which these experiences take place, and, more importantly, to the emotional dimension surrounding care. These emotions emerge from the relational nature of care (the relation between the caregiver and the elderly, between the caregiver and his or her nuclear family and the history of these relationships), from the reasons and motivations carers have to provide care, and from their ideals of a desirable care situation and how close or far they are from these ideals. The interplay between these aspects determines the intensity of the care experience and their complexity was grasped with a qualitative approach.

The key conclusion of this study is that the experience of care is complex. Care may be defined by a certain set of tasks, but that does not explain how carers experience care; reducing care to a specific set of tasks reduces the experience far too much. For the same tasks, some carers experience high levels of pressure, while others don't. The experience of care may be constrained by certain contextual factors (e.g. the elder's health, the family's financial standing, the carer's personal situation or the support they may receive, among others), but again, the set of contextual factors does not fully explain how caregivers experience care. Though tasks and constraints may increase the intensity of the experience, the emotional dimension of care can alleviate daily pressures and lighten the everyday life of main carers. The emotional dimension can also make the experience of care unbearable. The emotions involved in the care experience, in addition and in relation to care tasks and the care context, allow for a full understanding of the experience of care.

Aside from highlighting the complexity and importance of the emotional dimension of care to understand the care experience, this study also brings to light that caring for an elderly parent or parent-in-law is work. It is mostly invisible work and carried out mostly by women. Some carers receive support from their siblings, the very few who are financially well off are able to pay someone to share caregiving tasks and those who live in financially vulnerable situations may receive some (minimal, insufficient, mostly symbolic) help from the government. Many caregivers, however, are completely alone and unsupported in their otherwise silent, invisible, full-time and emotional care work.

The following sections develop these ideas further, highlighting as well the recognition of the value of qualitative methodologies to better grasp the experience of care and with reflections for the development of public policy for elderly care and the recognition of care as a shared social responsibility. This concluding chapter recognises, at the end, that while several questions have been answered, other questions remain to motivate future research.

Macro perspective of care in Chile: The social distribution of care

The first part of this thesis describes and analyses the macro dimension of elderly care. It recognises the characteristics of the elderly care phenomenon in Chile and its social distribution. It studies the role of the government in Chile's elderly care regime, how it evolved and the challenges it faces. By studying the social distribution of care and the role of the government, the thesis unveiled the persistence of social inequalities related to elderly care and the real nature of the care crisis in Chile.

The Chilean care regime

After reviewing the social policies available in Chile to support elderly care together with the actual experience of care, this study concludes that the social responsibility for elderly dependency is taken up almost exclusively by families. And taken up by women therein. When it comes to elderly care and despite some recent progress, Chile's elderly care regime is an unsupported familialistic regime or, drawing from Saraceno's (2010) terminology, a familialistic by default regime. In the Latin American context, where all countries are, to one extent or another, familialistic, the Chilean welfare state has been labelled as a state productivist (Martínez 2008). A state productivist regime is one in which the State has begun taking a more important role in insuring against social risks where market failures exist and supporting groups who cannot access the market. In a state productivist familialistic regime, in theory, social protection still relies heavily on the private domain as a way to ensure social protection against risks, one of which is caring for the dependent elderly.

The Chilean government has begun taking a more active role in elderly care. At the very least it is an issue currently discussed in the public agenda and there are initiatives in place. The Office of the President has led some recent efforts and made the promise to further develop policies for elderly care. From the return to democracy in the 1990s, the Chilean government has expanded its role in elderly care with a stronger push in recent years. Elderly care is already in the political discourse, recognising the importance and urgency of the phenomenon. It is an important first step in the development of any public support. Dedicated institutions to coordinate the development and implementation of elderly care policies (e.g. SENAMA) exist, providing the institutional basis from which to expand current programmes and develop future initiatives. Most recently, the Government has announced the creation of a National Subsystem of Care and Support that promises to advance towards a more equitable distribution of elderly care among society's actors.

An analysis of the coverage of these policies, key informant reports and the specific experiences of care weakens the argument that Chile is supporting and or alleviating families in their elderly care responsibilities. The level of policy development is incomplete. The State, despite encouraging developments is not a relevant actor in supporting elderly care or in advancing towards an equitable social redistribution.

The universal basic solidarity pension guarantees a minimum pension for all elderly, but the amount (around 135 euros a month) is too low to cover the basic needs of a dependent elderly. The GES health guarantees provide free universal health coverage for a specific set of pathologies but out-of-pocket expenditure in Chile remains one of the highest in the OECD and families with a dependent elderly usually engage in debt to cover for health care. SENAMA's programmes, following the subsidiarity principle of public policy in Chile, offers support for families in vulnerable socioeconomic situations, but coverage and participation in the programmes depend on municipalities' willingness to implement them and coverage is limited to a few families only. For example, only 14 SENAMA-sponsored day centres exist. Families that live in municipalities that do not choose to engage in SENAMA's programmes do not have access to any elderly support programmes. For non-poor caregivers, the majority of caregivers, the State offers no support as they do not meet the eligibility thresholds of socioeconomic vulnerability or live in a municipality that does not offer any service.

For the majority of caregivers, the care regime is one of familialism by default. Elderly care in Chile remains largely the responsibility of female family members in informal, unpaid arrangements with little or inexistent support from the Government.

The limits of the care regime to grasp the reality of elderly care in Chile

A study of Chile's policy developments in elderly care and the discourse stating the importance of this issue (such as the speech given by the President at the beginning of her mandate in 2014 when she announced the creation of the SNAC) we can conclude that Chile, in the continuum of familialism-de-familialism is moving in a direction of de-familialism. COSAM's programmes to support carers of elderly with dementia, SENAMA's care centres, long term care institutions and Home Care programme and the announcement of a National System of Care and Support, all read and sound promising advances. However, from the evidence of the coverage of the existing programs, the magnitude of the needs covered, and the real steps taken to implement the national system of care and support, we cannot conclude that there is a factual move towards a more supported familialism even less to a de-familialisation.

As coverage is low, the responsibility for care relies heavily on families. Most caregivers cannot access State services because they either do not meet the vulnerability thresholds or because they do not live in a municipality offering the services. For those who do, the services received offer valuable recognition, but do not provide a meaningful redistribution of the care responsibility. Also, most caregivers cannot access the market and externalise care tasks. The community, except for a few cases where neighbours participate in the care arrangement or the Church serves as a source of respite, is, at best, a minor actor. Given the policy developments in Chile, there is the intention for the government to take a more active role in elderly care. Scaling up coverage of the current policies and fulfilling the announced developments may contribute to actually producing that shift.

Given that policies cover a small fraction of the care experience and a large part of the care phenomenon takes place outside the scope of any policy, a macro-level based typology of elderly care misses how care is actually experienced. Though Chile's regime is one of unsupported familialism, the label does not fully portray what it means to live under such a regime for those who provide care. In combining a macro- and a qualitative micro-level analysis of elderly care in Chile, this study offers a more nuanced and detailed analysis of the phenomenon. It offers a more comprehensive outlook of the experiences of carers and the potential for a better understanding of the gaps to inform future policy.

Reducing the elderly care phenomenon to a care regime typology is also limited on another dimension: gender. It is true that in Chile the elderly care risks are concentrated inside families. However, the name "familialistic" allocated to the care regime in Chile is somehow biased, as women deserve a correct acknowledgment for their responsibility in assuming the risk of elderly care. The notion of a familialistic regime points to the fact that the main elderly care responsibilities lies in families. In Chile this is absolutely the case. A more specific and honest appraisal would recognise that the main responsibilities for the elderly care rely almost exclusively among women inside a family – with the exception of the financial responsibilities that usually rely on men.

Some 87% of informal caregivers in Chile are women. They dedicate their entire or almost entire time to care for the elderly. They are women who juggle between many other responsibilities; they are women who experience the intensity of the care experience. For the purposes of this research I could only find three male caregivers. In all three cases, they became the main caregivers because there was no woman available to provide care. Men usually offer financial support, help sporadically with the physically heavy tasks and sometimes provide emotional support to female carers.

In the few cases where elderly care policies exist, they do not help to de-genderize the distribution of caring tasks. Their design reinforces women's role as carers. They do not encourage men to participate as carers (e.g. the support given to family carers by the Home Care programme does not encourage a more equitable familiar distribution of care, but rather, support women's role as caregivers through monetary compensation; there is no mechanism in the Home Care programme to encourage men's participation in elderly care).

Given the gender-biased distribution of care within families, it is more appropriate to refer to the Chilean care regime as a "women-within-families regime", a "womenised regime" or a "gender-biased unsupported familialistic regime".

Current inequalities in care

The current social organisation of elderly care in Chile leads to the creation and maintenance of socioeconomic and gender inequalities. These inequalities are visible in terms of who carries out care work (mostly women), the gendered distribution of tasks carried out (men contribute to the physical work and financing but are completely absent of any intimate care tasks), the support received (men caregivers receive more support from siblings and community) and the long-term implications for carers of carrying out work without pay or recognition (carers remain out of the labour force and do not save for retirement, for example). Women are more likely to become caregivers than men, and more likely to experience the associated daily constraints. Women of lower socioeconomic status may also face strong financial constraints which will make them more vulnerable to experience care with a higher intensity.

The socioeconomic inequalities

The financial implications of care for the family are an objective constraint: they are difficult and hard for everyone. The direct financial implication of care is related to the costs of providing care, there is also an indirect implication and it is related to the carers' opportunity costs of not being able to work for income.

All elderly in Chile have a guaranteed basic solidarity pension of around 135 euros. This amount is below the poverty line and does not cover an elder's basic needs. Elderly in need of care cannot pay for their own care (only very few benefit from pensions high enough to support their care needs). Families caring for the elderly must contribute financially, out of their pockets, to meet care needs. The financial responsibility for elderly care thus falls particularly heavily on families with a severely dependent elderly who require higher care costs and on lower-income families who spend a larger share of their income in care, thus maintaining socioeconomic inequalities. As Saraceno (2010) pointed out, the fewer public services provide, the more the recourse to family or market care. This mechanism places a heavier weight on family carers particularly those in low-income households who cannot access to the market.

Saraceno also notes that given the difficulties in accessing the market, the lower the parents' socioeconomic status, the higher their (female) children's involvement in care. Also, the lower the children's socioeconomic status, the higher their involvement in direct care.

Care also reinforces socioeconomic inequality through the fact that carers who don't work for pay as a parallel activity do not receive income, do not maintain or build their human capital and do not save for a future pension. When they retire and become dependent, it is very likely that their families will have to support their care financially, reinstating the dependence on the family for care and maintaining their socioeconomic vulnerabilities.

Also, carers from more disadvantaged socioeconomic groups showed less motivation to combine paid employment with care work and to use that income to delegate part of the caring responsibilities, leading them to having fewer possibilities to pay for care. For lower socioeconomic status homes, care work is incompatible with paid work and delegation, most likely because the job opportunities available for them are unlikely to allow paying for an external caregiver. The only exceptions seen in this study were cases of extreme vulnerability where carers showed a desired to work to be able to make ends meet and feed their family.

Some low-income carers facing financial constraints do not question their carer role, they don't consider the possibility of combining caregiving with paid work. Caring, for non-working low-income carers is what they should do. Some framed this obligation as a way to reciprocate to the elderly, to give back to them. Other reasons include love towards their respective parent or parent-in-law, because it is the way that things should be or because they expect their own daughters or sons to follow their example and care for them in the future. These beliefs prevent carers from taking on paid work and increase the likelihood that they will experience financial constraints.

These beliefs take place under a familialistic care regime with very limited options to externalise care, particularly for middle and low-income carers who cannot access the market. It is possible that more women would be able to combine care work with a paid activity if the government or the community played a more active role in supporting women to access external caregivers', through conciliation policies. It is possible that, in a scenario with conciliation policies, low-income carers would have different care ideals and beliefs about their reasons to care and would be more willing to combine a paid job with their caregiving work.

In this line, Martin (2015) argues that in unsupported familialism schemes like the one in Chile, the extended family solidarity and protection offered by relatives is the result of the absence of governmental support. Without government support, families are *forced and required* to assume caring responsibilities. They *have to do so* as there isn't any real alternative. This would also explain the high and persistent poverty levels in countries under this care regime. Family solidarity is not a way to reduce inequalities, but rather a factor that increases them.

Relationship between socioeconomic status and the intensity of care

Importantly, and as strong as their financial constraints may be, lower-income carers from this research do not necessarily have a more intense care experience as compared to those on a better economic standing.

Higher-income carers tend to have a more individualistic orientation towards care and their life, as compared to carers from lower-income households. For the individualistically oriented, caring can be experienced with high intensity by hindering the accomplishment of higher income carers' personal interests, which go beyond the provision of elderly care. The relationship they have with their relatives and with the elderly will affect the intensity of their experience as well. Particularly difficult for high-income carers is the organisation and management of the external care support; conflicts between domestic service and health professionals were difficult and unpleasant. The frailty of the arrangement (in cases that external carers don't come to work, for example) also increases the intensity of the experience.

The scarcity of monetary resources in lower middle-income carers was a matter of conflict among siblings, and conflict and negative relationships among relatives augmented the intensity of the caring experience.

Middle-income carers are the most invisible population in terms of their elderly caring role; they felt this invisibility in their everyday lives. They cannot access government services as they do not meet their eligibility thresholds and cannot access the market as they don't have enough income to externalise part of the care tasks. Furthermore, middle-income caregivers in this study were less likely to receive support from their families. The focalization principle that guides the offering of social programmes in Chile, especially those related to elderly care result in a vast majority of the population remaining unprotected when they still have a strong need for protection. The medical and care costs associated to elderly dependency, for example, can lead them to engage in substantial debt.

Middle-income caregivers were aware of their invisibility and complete lack of support and complete absence of conciliation policies. Some of them worked for pay in addition to their care work to maintain their living standards and pay for the elderly care expenses. Yet, working for pay did not necessarily mean that they had the financial means to pay for good quality elderly care. Middle-income carers who remained out of the labour force felt it as unfair the fact that they could not apply to any benefits from the government because it is the family income that counts for receiving benefits, and this family income is, in those cases, only provided by others in the family (usually men). The fact that carers (usually women) dedicate themselves to elderly care without receiving any monetary compensation implies that they do not contribute to their pension savings. In caring, they compromise their future financial stability. Middle-income caregivers in this study believe they are invisible for the State and their families and they strongly believe they should deserve State support. In this sense, family compensation may reduce inequalities among elderlies in need of care, but increases inequalities between family carers. The higher the amount of care left to families, the greater the role that socioeconomic and gender differences play in the ability to substitute one's own care. Given the gender-biased obligation to care, unsupported familialism, in turn, affects both gender inequality and inequalities among women (Saraceno 2010, Saraceno and Keck 2010).

Gender inequality

In terms of public policies and gender equity, in general, policies implemented since the beginning of the XXIst century have attempted to mitigate gender inequalities in various domains. They have been relatively successful in reducing inequalities in financial security, education and health. Interventions have been less successful however in promoting women's employment, in promoting a culture of joint responsibility in the care of dependent people and in developing institutional policies that allow for greater equality in employment and care. Despite the advances, strong gender inequalities remain in the social protection system (Robles 2012).

Also, women have held less power in institutional and political spaces. Women provide most of the care and bear most of its effects, but their weaker institutional representation has limited the possibility of considering the gender bias in the distribution of care as an important issue (Aguirre 2007). Policies and government initiatives around care have occupied a secondary status. When they exist, they are seen as a benefit for women, resulting in a symbolic and social devaluation of care work and enduring the assumption that care is feminine responsibility (Provoste 2012). Public policies and programmes continue to consider care as women's issue and one that the State may (or may not) support. Care is not recognised as a universal human right. There is no discussion around the need to redefine gender care roles (Pautassi 2007).

How women and men experience care in this study shows the gendered nature of care. Notably, men are the minority when it comes to care. In the few instances when they are the main caregivers it is only because there are no women in the family to do it, as is the case for a male single child, or because other women simply cannot provide care, as is the case when a female sibling is also dependent.

When men do care, they care in different ways. Male main caregivers do not provide intimate care. They find someone from their social support network to do it. And for men, unlike women, it is easy to find someone because men's social support network is more willing to support them when compared to women carers. Indeed, men carers receive more help from relatives, neighbours, employers and co-workers. This support allows men to maintain good social relationships when compared to women.

Women experience care differently. First and foremost, they are the ones who will take on the responsibility of becoming the main caregiver of an elderly parent or parent-in-law. In cases of large phratry with men siblings, women will take on the role. When the elderly has only male children, it will be a daughter-in-law who assumes the role of the main carer, not a son.

These caring patterns represent and maintain broader gender inequalities. Women are more likely to take on the role of carers, which transforms their lives and their opportunities. The stagnation of gender roles in care tasks are culturally rooted both at the individual and at the State level. They do not reflect Chile's economic development or ambitions for development.

The importance of culturally-rooted gendered norms around care is also evident between partners within a family that provides care to an elderly parent or parent-in-law. Male partners of female caregivers are not expected to provide strong support with the elderly care. More often in this study, conflict does not arise within a couple as a result of a spouse caring for an elderly, even though in all cases the spousal relationship changed as a result of care. This situation – of male partners not being involved – was stronger among low-socioeconomic cases. In upper-socioeconomic status cases, women expected their husbands to be more than just the breadwinner, although in most of the cases, husbands' role in the family was just that.

Policies in place maintain the gender-biased distribution of care. Public services to support care for the elderly, whether from SENAMA, the Ministry of Health or the Foundation for Families (under the eaves of the Sociocultural Direction of the Presidency) do not include as part of their objectives promoting a gender-equal distribution of care.

The care crisis in Chile: A problem of the social distribution and invisibility of care

Chile is experiencing social and demographic changes that affect and will affect the composition of elderly people and potential caregivers. The country is one of the most aged in Latin America, second to Uruguay. In 2015, the percentage of elderly people reached 11%, compared with 8% for the region. Furthermore, by 2035, Chile will become the country with the highest share of elderly population in Latin America, reaching 20% (UN 2015). Chile's demographic and epidemiological figures are in line with those that refer to a potential care deficit: Chile's population is aging and broader social changes (e.g. women's progressive inclusion in the labour force) have contributed to a fall in the availability of the traditional caregivers (women within families) opening the doors to a potential care crisis.

The evidence at the macro- and micro-level presented in this study shows that Chile is experiencing a care crisis. The care crisis generally refers to a deficit in the amount of caregivers in relation to the needs of elderly caregivers (Arriagada 2013). This study suggests, however, that the care crisis is not only about a current or projected deficit of caregivers. It is a crisis of the social distribution of care caused by an unfair distribution of a social responsibility.

The crisis seen in this study and in caregiver's experiences refers to the social organisation of elderly care in Chile and the lack of a shared social responsibility. The unsupported familialistic care regime in Chile leads to social inequalities. It leads to a high intensity of the elderly care experiences for the many women who dedicate their life to care for their elderly relatives. It is a crisis because it creates and reproduces economic and gender inequalities. As currently stipulated, the care crisis refers to a deficit in the private sphere alone: it is framed in the context of a lack of women to take care of the elderly. The actual crisis this study finds refers to a deficit in the public sphere: the lack of policies and dearth of government attention to the issue signals a deficit in the public sphere's responsibility for what is a social risk.

At the micro level, the crisis is felt every day. The lack of support means that families have no other option than to provide care for the elderly. The non-equitable social distribution of the social risk also means that there is little recognition by the State, community or social networks for taking on the responsibility for elderly care. For the majority of caregivers, their work goes unrecognised.

At the core of the care crisis is the lack of support and lack of recognition is a weak valuation of the care activity. Care is an activity that exists only in the private sphere and is rarely considered as work. Both the lack of support and recognition are potential causes of feelings of pressure in caregivers' daily life. Experts interviewed for this study agreed that the lack of value for care and the delay and weak role of the government in elderly care policies is due to the lack of value that the Chilean society assigns to the elderly. The elderly are considered second-class citizens, as they are no longer 'productive'.

Coincidentally, Huenchuán (2016) illustrates the low social recognition the elderly have in Chile, in a comparative study on aging and public institutions in Latin America. She shows, for example, that the founding of Chile's SENAMA was not the result of an increased societal awareness of the importance of the elderly or a recognition elderly's contribution to society, as it is the case in most Latin American national services for the elderly. Quite the opposite, SENAMA was tasked with the goal of raising awareness and sensitise the populaion about the value of the elderly given the low recognition of the elderly in Chile.

This lack of social valuation of the elderly care was strongly felt by the caregivers in their every day lives. Irrespective of their socioeconomic status, their age and family condition, most caregivers wanted more recognition for their care work.

High- and middle-income carers requested greater recognition of their work by their close relatives. They would like their relatives to be aware of the work they do; they feel upset and regret their roles of caregivers when their work is not acknowledged. Carers from lower socioeconomic status claimed for a stronger visibility from the government for the work they do. This is not surprising in the context of a government that orients public policy under a subsidiarity scheme. In it, only the lower income households expect to receive public support.

Interestingly, those who participate in the government initiatives, such as the Home Care programme, one of the most gratifying aspect of their participation is the value and recognition they receive, realising that their activity is no longer invisible and that they are not alone. The greatest value of the programme is not the direct service provided, as it amounts for only two hours of respite per week for nine months a year.

The objective of the announced National Subsystem of Care and Support remains as relevant as ever: awareness-raising on the importance of an equally-shared responsibility for elderly care.

In part, care is also socially devalued and invisible because mainly women carry it out, and women are seen as natural caregivers. Interestingly, as seen in this study, in the few instances when men were the main carers, their job was praised and recognised by their social environment. Male carers, unlike female carers, were supported by their relatives, co-workers, employers and neighbours; they are valued as carers. Women are not valued when they are the main carers for the elderly, but they account for 86% of carers in the country.

Overcoming the care crisis means transiting towards a more equitable distribution of elderly care among societal actors (the State, the family, the market and the community). It also means shifting the gender distribution of this responsibility inside families.

The micro perspective of care: the care experience

The third part of this thesis is dedicated to the experience of elderly care. It analyses the daily investment of family carers of an elderly parent or parent-in-law. This part answers to the questions of whom and under what conditions and situations the job of caring for the elderly takes place and what shapes the intensity of the care experience, acknowledging the limitations of the commonly used quantitative methodologies to study the intensity of the care experience.

The complexity of the care experience

Being the main carer of an elderly parent or parent-in-law is not easy for any of the cases of the study. Rendering care to an elderly parent or parent-in-law is hard work, practically all carers are exhausted by the end of the day. It involves physical work, attention and disposition. Care involves a myriad of different tasks. It involves responsibilities that go beyond direct care (e.g. toileting, administering medicine), such as providing company, surveillance, managing external carers and health appointments, etc. Outlining the tasks and understanding which caregivers carry out which tasks is a necessary and important first approach to understanding of the experience of caregivers. For some carers the most difficult tasks are related to the elderlies' personal and intimate care because of the physical demands and, more importantly because of the emotional underpinnings of seeing their parent's dependency. Cooking, cleaning and doing the laundry are, in some cases, experienced as a respite from the direct caring activities. Surveillance is a constant source of difficulty for all carers as it requires being aware, attentive and available at all times. Irrespective of the task, a constant finding of this study is that no task unequivocally leads to a greater or lesser experience of pressure.

Reducing the experience of care to the tasks carried out ignores how situations can constrain how caregivers' experience the tasks they carry out. Difficult economic conditions, caregivers' advanced age, multiple caring demands, the level of dependency of the elderly and the existence of formal and social support can all become constraints in the experience of care.

Depending on the situation, carers are subject to stronger or weaker constraints, and some of those constraints are more objective than others. A bad financial situation is an objective constraint. The less objective constraints mean that similar situations are not experienced in the same way by different carers. For example, multiple caring demands (e.g. caring for elderly parents and grandchildren at the same time) are experienced as a constraint by some carers as it involves more tasks to be carried out; for other carers multiple caring demands are a resource as children offer respite from the elderly care and vice versa. Similarly, having a paid job, receiving formal support or cohabiting with the elderly in need of care are not experienced in the same way by all carers.

For the few that receive it, informal support from siblings was experienced as a resource if it was aligned to carers' expectations regarding siblings' involvement. The same can be said for formal support from public programmes. The very few who are eligible and participate in government-sponsored programmes may value the public recognition of their work, but may not reduce the intensity of care if they do not align with carers' expectations and needs. For example, support programs that inform on how to provide care to the elderly could be very beneficial for carers at the beginning of their role. However, carers who have been providing elderly care for a long period felt guilty, sad and with higher levels of pressure after learning that the tasks they have been providing should and must be done differently.

Further still, the particular situations fail to explain why they lead some caregivers to experience care more intensely than others. They fail to fully explain the sources of carers' experience of pressure. Despite the presence of contextual difficulties, caring can be experienced positively. Despite the absence of contextual difficulties, it could be experienced intensely. Difficult situations do not automatically translate into pressure to caregivers' experiences.

The emotional dimension of care

Care, as this study shows, is an inherently emotional work and some of these emotions are shaped by the relational nature of the work. Care is a relationship; caregivers care for and about someone, involving emotions. The emotional dimension of care allows understanding how situations and difficulties translate into daily pressures, or not. Acknowledging the emotional dimension of care requires accounting for carer's relationships, the history of these relationships, their motivations to provide care and their ideal care situations. The relations carers hold with their social environment – in the context of their historical relationships – are key to understand how carers experience their daily life in that role. Relationships can make a very difficult caring situation to be experienced with positive feelings. Relationships that give rise to conflict can make a seemingly comfortable care situation become unbearable.

The social environment in the context of care includes, most notably, the historical and current relationship with their elderly parents or parents-in-law and other members of their family. This explains how, for example, caregivers who see care as an opportunity to reshape a historically difficult situation with their parents or parents-in-law feel grateful even if they are exposed to several potentially constraining situations. Similarly, the history and type of relationship the carer holds with their siblings will determine what the carer expects from them and whether they experience their involvement as a resource or constraint. This study shows that the relational component cannot be left aside when studying the intensity of the care experiences.

Finally, the carer's own personal view of themselves in the role of carer and their ideals of care shape their interpretations and emotional reactions to the tasks and situations. The experience of care is also shaped, to a lesser extent, by carers' motivations and the reasons that led him or her to assume the role. They are rooted in cultural norms and also in the family social relationships. Carers who assumed the role voluntarily experience less pressure than those who feel were obliged. Carers whose situation is far from their ideal care situation also experience greater pressure in their daily life as carers.

Previous research has noted that emotions (Tronto 1993, Hoschild 2003, Montaño y Calderón 2010, Twig 2010) and the emotional component of relationships (Le Bihan and Mallon 2017) are a fundamental component of care work. This study's findings support this conclusion in the context of an emerging economy and a familialistic care regime and contributed to its understanding in an understudied context. This study also extends the complexity of the care experience and the important of the emotional dimension in shaping the intensity of the care experience, including not only the relational part of the care relationship but also the carer's own view of themselves in the role and their ideals of care as another source of emotions and of a potential source of pressure.

This research found that the intensity of the care experience is not solely determined by the tasks and hours dedicated to providing direct care, neither solely by the difficulties of the context in which care takes place. To really understand the care intensity, the emotional dimension of the caregivers daily life should be taken into account, as it will add or not, to the intensity of the experience. The intensity of the care experience is then the result of a combination of objective factors, different contexts and subjective perspectives adjudicated by the emotional dimension of the care.

The qualitative methodology as a way to understand the complexity of the care experience

Given then the complexity of the care experience, a qualitative methodological approach is best suited to understand it. Care is a social experience with important emotional implications. It is emotional work. Quantitative methodology usually reduces care to a set of specific tasks or hours spend carrying them out. But care is more than the sum of tasks, more than specific hours spent providing direct care in a context of more or less difficult situations.

A quantitative task- or time-based approach hides the real intensities and characteristics of the care experience. It fails to grasp the different sources of pressure. Caring involves tasks and responsibilities that are not direct care (e.g. surveillance, managing external carers and health appointments, etc.). Usually, these non-direct care responsibilities are not counted in quantitative studies as part of care work. At this simple level, task- or time-based approaches fail to understand how carers who only provide a few hours of care a day experience strong feelings of pressure.

As this study shows, the number of hours or the tasks carried out does not determine the intensity of the care experience. Carers can work long hours providing care and still feel comfortable and find the experience emotionally rewarding. Caregivers might also carry out only a few tasks and spend a small amount of hours dedicated to care but still experience pressure. Although tasks and time spent are an important part of the workload and experience of caregivers, they do not capture its complexity. Care is embedded in a structure of societal norms of what care is and should be and is embedded in a history of changing relationships. Care is, above all, emotional work.

The qualitative methodology adopted in this research captures the complexity of the phenomenon and its social and emotional nature. It also does so by considering it value-neutral; it does not impose care as a negative experience (e.g. a burden). Approached negatively or reduced to specific quantifiable indicators leads to a biased account of caregivers' experiences, and to an underestimation of the social consequences care brings to caregivers. The qualitative methodology allowed contextualizing and understanding the phenomenon as it occurs in carer's ordinary environment. The qualitative methodology captured the care experience not as a frequency of hours spent and tasks rendered, but as a complex experience shaped by social relations and emotions.

A qualitative approach to study the experience of care complements a macro analysis of the social distribution of care. A macro analysis of the policies in place suggests a care regime with some support from the State, but fails to understand how carers experience that support, what they expect from it and what they receive from it. A purely macro analyses would not identify, for example, that the value carers obtain from the current government programmes is the recognition, not the service or good itself.

This does not mean that quantitative studies of the elderly care phenomenon are not valuable. They have been in Chile, as well as in other countries, a valuable starting point to bring the subject to light. They have raised awareness of the magnitude of the certain aspects of the problem. Qualitative methodologies allow for a deeper understanding of the phenomenon. Quantitative methodologies can then draw on this deeper understanding to identify better indicators of the intensity of care and including indicators of emotional dimension of care.

Insights for the development of elderly care public policy

This study provides a comprehensive understanding of what it means to care for an elderly parent or parent-in-law in Chile. The macro- and micro-level analysis of elderly care in Chile complement each other in the understanding of this complex phenomenon and provide a unique vantage point to suggest policy development. Indeed, characterising the Chilean elderly care regime in one typology and studying the government's recent policy development in elderly care provides a very limited picture of what it means to live in such a regime for those who provide care. A macro-level analysis of care policies does not say much about what the day-to-day experience is like, how intense it is to provide care to an elderly family member, where the experience of pressure comes from or what carer's needs and expectations are. Still, the micro-level analysis of the caring experience is best understood in its more general context. Taken together, these elements reveal a reality that has remained understudied by the social sciences and underdeveloped by the public sector.

This study has shown that the Chilean government has made important efforts to protect the most vulnerable population since the return to democracy in the 1990s. It has followed, for the most part, a strategy of subsidiarity, to correct for any market failures. Important advances have been made to support against health and financial risks and to expand access to and quality of education. These efforts have been especially relevant for people living under poverty. Steps have also been taken to increase the scope of protection to other groups that are subject to vulnerability, such as young children, women and the elderly. Still, social protection relies heavily on the private domain to ensure social protection against risks, such as being an elderly in need of care. The State plays a relevant role among groups experiencing the highest vulnerability and, with the exception of few policies with universal coverage (such as the public health system of explicit guarantees and the basic solidarity pension) is practically absent for the rest of the population.

Thus, this study finds that the elderly care regime in Chile is an unsupported familialism. The analysis of the experience of care also shows that, for many women caregivers, elderly care is seen as an obligation. It is seldom a choice. When carers see themselves as being obliged to adopt the role, they have a high chance of experiencing care with pressure. Indeed, many people care because there is no other option available, many women care because for it is unthinkable that men adopt that role and many carers do it alone, with little or no support from the rest of the family, from the State or from the community. A more equal distribution of care among societal actors is necessary to alleviate the feelings of pressure on caregivers and to remediate the inequalities that result from this social distribution of care.

In terms of elderly care and since the creation of SENAMA, the announcement of the creation of a National Subsystem of Care and Support is the most recent and salient step taken by the Government to recognise elderly care and advance towards a more equitable distribution among society's actors. Almost two years after its announcement, however, there is little information available about the shape it will take. The fact that it has been mentioned at the highest political level is an important step. Importantly, this initiative is the only one that so far that targets the caregiver as one of its main objective population. Up until now, the caregiver has not been considered the target of practically any policy even though their situation is one of economic, social and emotional vulnerability.

There is practically no programme sponsored by SENAMA or by any other governmental institution that focuses on the caregiver as their objective population. Primary mental health centres (COSAMs) offer support to caregivers of elderly with Dementia. Two SENAMA-sponsored programmes – with very low coverage – give respite to the caregiver (e.g. the Home Care and Day Care Centre programmes) but their ultimate objective is not the caregiver, but supporting the caregiver to increase quality of care received by the elderly. SENAMA's mission is to support the elderly, not the caregivers.

A first step towards improving the lives of caregivers is considering caregivers as the direct objective of public policy programmes. These programmes should be integrated and complement the broader framework of policies that support the elderly. In this regard, the SNAC is the first national initiative that considers the caregivers as one of its target. It should consider programmes for caregivers in conjunction with policies for the elderly.

Policies to support elderly care do exist, but in addition to their minimal coverage, they cover only a small portion of caring needs. The Chilean State's role in elderly care has increased but it remains underdeveloped, particularly when compared to other domains of social protection (e.g. health and childcare). It is ultimately the family, and women therein, who take the large remaining responsibility for elderly care.

Despite recent policy developments and announcements, there is still room for improvement. Any policy development that follows should be part of a broad framework that creates a more equal distribution of care across the family, the State, the market and the community. Several obstacles remain to achieve this goal, as shown by this study. These include the lack of coordination and communication between elderly-related services (e.g. primary health centres and SENAMA) and the slow recognition of elderly care as a shared social responsibility. Chile's centralised policy development but de-centralised implementation model means that social policies originate at the national administrative and political centre but depend on individual municipalities for implementation. This model makes elderly support care programmes to be implemented in the few municipalities that consider elderly care as a relevant issue. It leads to an unequal distribution of support across municipalities.

Experts interviewed in this study suggested five key issues that contribute to the current state of affairs in elderly care policy: i) low coverage of existing programmes, ii) absence of support for middle-income households, iii) low pension-related income, iv) the absence of conciliation policies that allow women to balance care work with paid employment and v) the fact that current elderly care policies maintain gender inequalities.

In studying the intensity of the care experience, this study identifies policy issues that require urgent consideration to advance towards a more equitable distribution of the elderly care responsibilities and to reduce the intensity of the caregiving experience: i) increase coverage for existing programmes and services, ii) broaden eligibility criteria to better target carers with an intense caregiving experience, iii) expand the issues targeted by social programmes and services to better alleviate the intensity of the care experience and iv) engage community-based organisations. Reformulating elderly care policy along these lines will promote support that overcomes several of the abovementioned obstacles identified in this study.

1. Increase the coverage of existing elderly care programmes.

The macro-level analysis identifies a number of different programmes available to support elderly care. At least six programmes exist, most sponsored by SENAMA. This may lead to the incorrect conclusion that support for elderly care in Chile is adequate. The fact is, however, that the population that can really access these programmes is minimal in comparison to the population that is in need for these programmes. For example, only a 0.3% of the potential population participate in Day Care Centres and waiting lists are so long that when places become available the eligible elder may already have passed away. Only the socioeconomically vulnerable population is eligible. As a result, a large part of the population in need remains outside the scope of this programme and all other socioeconomically targeted programmes. Mostly all households lack the economic means to meet the elderly care needs in any form other than unpaid, informal family care provided by a full-time daughter or daughter-in-law carer.

Coverage is further limited by the municipality-oriented nature of service provision. It is up to the municipality to choose whether or not to implement a SENAMA-sponsored programme. Thus, depending on the municipality, vulnerable caregivers will have access to different care support programmes, if any. In the current state of affairs, municipalities can opt not to implement any elderly care programmes. Many times, municipalities do not have the administrative capacity to implement programmes, even if they have sufficient elderly in their population to warrant implementation. In others, the number of elderly in the population is deemed too low, and there is no possibility for different municipalities to join efforts and implement programmes jointly. This creates territorial differences that generate inequality.

Coverage is low in large part because of the insufficient financing of the existing elderly care programmes. For example, the budget for the *Cuidados Domiciliarios* (Home Care) programme which supports caregivers and offers them respite for two hours a week amounts to less than 10% of the estimated cost for a formal home-based care system (Matus-Lopez and Cid 2014). Similarly, and although there are no estimates for the cost of day care centres and elderly care residences, international evidence shows that these programmes in Chile are also underfinanced (Genworth 2015 in Matus-Lopez 2015).

Apart from the financial constraints, caregivers in this study pointed to the perceived low quality and difficult accessibility of day care centres and elderly care residences as a reason for opting for full-time, informal, unpaid care by family members. The Home Care programme was valued not for the respite it offers but for the recognition of caregivers' work. Increasing the budget for these services can offer an opportunity to increase the quality of care and offer caregivers true respite.

2. Broaden the criteria for eligibility to public elderly care programmes

As previously mentioned, eligibility for current elderly care and support programmes is based on the household's socioeconomic level. Socioeconomic level is measured by a national instrument, the *Ficha de Protección Social*, which is also used to gauge eligibility to other social programmes. Only households with a dependent elderly and deemed vulnerable by the instrument are eligible to participate in SENAMA's programmes.

Eligibility to elderly care programmes does not consider caregivers' situations nor the intensity of their care experience. Basing eligibility solely on household's socioeconomic level ignores the emotional and relational nature of the caregiving experience. The intensity of the care experience should be considered as a factor for eligibility and an issue for direct intervention by elderly care programmes. It is not enough to only focus on the financial aspects to make them eligible participants, nor focus solely on the degree of dependency of the elderly. The extent of any financial support should be based on the household's financial situation, but the eligibility to access support and services should not be limited only to it.

This study has shown that caregivers' experience is highly associated to the relationship the carers maintain with the elderly, their siblings and with the reasons for which they adopted the role. These factors should be considered to determine eligibility. This way, programmes would target caregivers in need and promote their wellbeing.

Findings from this study show that caregivers from middle-income households received less support and were trapped in a situation in which they needed to work to maintain their households but lacked the means to externalise part of the care tasks. Middle-income household caregivers juggle work and care. In the context of an absolute absence of public policies to conciliate having a paid work and elderly care responsibilities, middle-income carers are by far the most invisible, they are not in the eyes of the public policies and they are neither able to receive private support. Furthermore, middle-income women who are not in the labour market are not able to save for their own pensions, increasing their possibilities of financial deprivation in their old age.

3. Expand services to alleviate the intensity of the care experience and reduce care-related inequalities

The emotional state of caregivers is of crucial importance for their daily caring experience. These components are not considered in current programmes and services for elderly care. They should not be left unconsidered when designing policies to alleviate the intensity of the care experience. Public elderly care policies should consider the specific needs of carers, as the experience of care is complex and diverse. Not all caregivers need the same kind of support. For example, for some women, difficulties to combine a paid activity with elderly care are a major difficulty; conciliation policies are of direct importance for them. For others, the ideal situation would be to receive a monetary compensation for providing elderly care; a conditional cash transfer system would be best suited for these carers. Programmes should provide support to caregivers that want to dedicate themselves to elderly care, but also give the option to de-familiarize elderly care by supporting access to quality elderly care residences or day care centres. This may prove costly, in that case, programmes should support a de-gendered familialism by supporting men's participation in elderly care.

Some caregivers adopt that role because they have no other choice, but they would rather prefer doing something different from elderly care, or combine that role with others. Elderly day care centres are an alternative to de-familialise, and offer main caregivers the opportunity to engage in paid work if so they wish. They can be especially beneficial for middle-income caregivers who want to combine a paid job with their caring responsibilities. Day care centres may also provide low-income caregivers the possibility to enter the labour market, as they usually stay away from paid work under the assumption that they cannot access good quality care for their elderly. Importantly, day care centres maintain the relational nature of the caregiving experience, as the elderly remains in close contact with his or her family. In Chile, there are only 14 centres in operation. They are available in only a small fraction of the country's 345 municipalities. Of these 14 centres, only one centre is dedicated to elderlies with cognitive dependency. The more general framework of conciliation policies can promote the balance between care work and a paid activity. Current difficulties to combine paid employment with caring responsibilities result in even further difficulties to escape poverty. The lack of conciliation policies results in that carers who work and care struggle with care-related unpredicted situations (e.g. hospitalization, an external carer not able to come to work, etc.).

There is an important gender dimension in balancing care and paid work. The evidence in this study finds a higher likelihood of informal support offered to male carers. Female carers with paid employment find less help than male carers at their working places to combine elderly care responsibilities with their employment. Government policies should not only develop conciliation policies, but address the associated gender dimension as well.

Conciliation policies should not only focus on formal employment, but should also consider self-employed women or women in informal jobs.

It is important that the government creates opportunities so that people caring for elderly relatives or those who were carers in the past can enter the labour market. The Chilean government should make an effort to increase women's labour participation (one of the lowest among Latin American countries), independent of their family status (daughter, mother, wife). Offering alternatives to caregiving can promote participation. They include balancing the role of men and women in care, , redistributing care responsibility not across family members so that it is not only one daughter who takes on the care responsibility, provide good quality and affordable options for externalising care, work against labour discrimination against women, and create schemes that recognise the capacities acquired in their work as caregivers.

Programmes that provide information on how to deliver care may be useful for caregivers, but attention should be given to the timing of the delivery. This research found that these initiatives were, contrary to the programme's expectations, a source of pressure for caregivers if the timing of the delivery was inadequate. Carers who have been providing care for many years receive information too late in their caring path, and they feel it's too late. They feel guilty if the way they have been providing care is different than what is presented in the programme.

4. Use the potential of communities to distribute caring responsibilities more equitably

In addition to families, the State and the market, communities constitute a relevant actor in the social distribution of care. Neighbours, religious communities and local organisations can and should play a relevant role in elderly care. In Chile, 96% of the elderly population with some dependency level does not receive any type of support from their communities (SENAMA 2009b). This was also evidenced by carers' experience in this study, community support was usually weak with the exception of few cases. Neighbours and carers' religious communities were important sources of support for a few caregivers, but they do not constitute a meaningful actor in the social organisation of care. Neighbours provide support in case of emergencies. Religious communities provide some degree of emotional support and respite. Community support is most relevant for low-income caregivers, who cannot count on market services to externalise part of the caring duties and face bigger financial constraints. The community supports low-income carers with some tasks in certain cases, notably neighbours providing surveillance to elderlies when the main caregiver has to leave the house for some more or less urgent, non-regular reason.

It is a large challenge to activate community networks and enhance the community's role in elderly care in Chile. As one key informant mentioned, during the military government all forms of communal support and participation were eliminated. The government has started taking action on this through the *Chile Cuida* programme. The programme trains and employs unemployed women or women seeking to increase income. Importantly, the programme draws on women from the same community in which they will work as caregivers. These women visit each elderly participating in the programme twice a week. However, as with all other elderly care programmes and policies offered by the government, the coverage is extremely low. As of today *Chile Cuida* is in operation in two municipalities in Santiago, excluding not only other municipalities from Santiago but, all the other regions of the country. A further and more comprehensive community development programme for elderly care should be promoted, one that goes beyond a few municipalities of the metropolitan area.

Questions for future research

Although this study has provided insight on the social distribution of care for the elderly in Chile and the experience of care for caregivers, several questions emerged. Answering them would allow for a deeper understanding of the phenomenon. Future studies dedicated to elderly care could explore, for example, the following issues:

- The political economy underlying the social distribution of different types of care (elderly care, childcare and care for disabled). As in many developed countries, development of policies to support elderly care lag those of childcare. Is the lag observed in Chile between care-oriented policies comparable to those of developed economies or is Chile's relative lack of policies to support elderly care special when compared to childcare or disabled people's care in other countries? What explains this gap and differences in the social organisation of care for the elderly and children?
- Chile, as other emerging economies, is rapidly evolving and the orientations to elderly care may be shifting alongside other rapid cultural changes. In this regard, how have attitudes and behaviours towards elderly care changed across generations?
- This study provides an overview of the elderly care programmes available in Chile and finds that although several programmes exist, their coverage is limited. As per the interviews with experts, this study promotes the scaling up of at least some of these programmes, but they lack a formal and comprehensive programme evaluation. To what extent are the programmes being developed achieving the goals proposed? To what extent do they promote a fairer distribution of care for the elderly in Chile? To what extent do they consider the experience of providing care in their design and evaluation?
- This study focused on the experience of daughters, sons and daughters-in-law in caring for their elderly parents or parents-in-law. It did not explore the experience of spouses who are the main caregivers. Future work could complement this study by focusing on this group of caregivers.
- This exploratory study highlighted the complex nature of the intensity of the care experience. It showed that emotions, relationships, motivations and expectations shape the intensity of the care experience. Future studies should go further and disentangle how these constructs relate to the care experience, by asking, for example, how do

emotions, motivations, expectations and relationships interrelate and contribute, individually and jointly to shaping the experience of care.

- This study explores care from the viewpoint of the caregiver and shows its complex, emotional nature. It highlights, for example, how policies and programmes largely ignore the position of the caregiver. Given the emotional nature of care, this study could be complemented by a careful rendition of the experience of care by the part of the elderly and other family members. This would illuminate on the types of care that elderly prefer and that better promote their position in society and why other family members remain largely uninvolved.
- Caring for an elderly parent, as we saw in this research, implies an investment and, in most cases, the postponement of personal interests and professional development by the part of the carer. One common motive of anguish among caregivers is their own future life, what will happen once the elderly is no longer alive, how they will fulfil their own life. This is a topic that deserves further research; in particularly how it can be tackled by public policies.
- Chile is a diverse country and this study covered a small fraction of the country, the metropolitan area of Santiago. Further research should concentrate on the experiences of family carers in other regions and across urban and rural areas.

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Appendix I. Interview guideline for key informants

Note: A Spanish version of this interview guideline was not applied in order and all questions were not asked to the key informants. The items discussed were related to there area of expertise and knowledge of each key informant.

1. Once older adults become dependent from other people to perform daily living activities (such as bathing, cooking, dressing, etc.), who is responsible for providing them with care? What is the role of the different actors of society in care provision: family, community, social and health institutions, market, etc? Are there instances of coordination and integration between these actors?
2. How do families organise themselves to provide care for their elderly? Are the care tasks shared within families or is it only one person who usually takes over? How is it decided who will be responsible for the elderly care?
3. What would be the most typical configuration of informal care in terms of who provides care and where (e.g main caregiver is a daughter living with the dependent parent, daughter-in-law, wife, non-cohabitant, external caregiver working at the same time, a caregiver combining paid work and care, etc.)?
4. What are the implications of care for the family caregivers (in their social life, their professional career, their health status, etc.)? What is the most difficult part for informal caregivers?
5. What are the implications of different care arrangements for the elderly person?
6. What are the major steps the government has taken to recognise and support elderly care? Can you please describe these steps and specific initiatives, if any? Do they target the elderly person or their caregiver? What are the benefits? Who is allowed to participate? Which institutions are in charge of its design and implementation?
7. What are the main challenges that the elderly care phenomenon in Chile faces?
8. What needs to be done to address the challenges facing the long-term care of the elderly?
9. What has hindered the development of a higher governmental commitment towards the elderly care, if any?
10. Do you think the issue of dependency has priority in the public agenda? Why or why not? If not, why is it not addressed directly in the social protection system, for example?
11. Who do you think should be responsible for Chile’s elderly care needs: families, the individuals themselves, the communities, the State, the market, a combination of them?

Appendix II. Interview guideline for caregivers

Note: A Spanish version of this guideline was used as a guide for the conversations with caregivers. Some questions were used to elicit carers' narrative of their life history and caring experiences. Most of the issues covered in the questions were covered spontaneously by caregivers through the interviews.

The objective of this conversation is to talk about your experience as the main elderly carer.

To start, could you please let me know whom you are responsible for care and since when did you adopt that role?

1. Do you live with the elderly you care for? Who else live with you?
2. Aside from you, who participates in the elderly care arrangement and in what way? If someone outside your family participates, how did that person come to help with care?
3. What does your daily routine look like? What are the tasks you carry out to provide care? Which are the most difficult for you and why? Which ones you enjoy the most?
4. How do you organise your life to provide care? How does care affects other aspects of your life (e.g. marital life, family life, employment, friendships, free time, etc.)?
5. How is your relationship with the elderly you care for? Has this relationship changed over the years? Why?
6. Did you ever expect you would take on the role as main carer? Why?
7. What do you think about your role? Is there anything you would like to change about it? What, if any, and why?
8. How do you think this situation will evolve in the next months? How would you like it to evolve?
9. Why is it you that became the main carer? What about the rest of the siblings? How do you consider this situation, fair, unfair, obvious, free, etc?
10. Have you ever though about externalising care? What do you think about that option?
11. What would be the ideal care situation for the elderly you care for? What would be your own ideal care situation if you become dependent?
12. Is there anything else you would like to share with me regarding your life and your experience as a caregiver?

Appendix III. Caregiver informed consent form

Note: A Spanish version of this form was read to all the study participants at the beginning of the interview.

You have been invited to participate in this study. This document contains information about the study. Before deciding whether to participate I will read the information, please ask me any questions you may have about it. Remember that your participation is totally voluntary.

Title of study: Elderly care in Chile, policies and experiences.

Principal investigator: Josefa Palacios Noguera, doctoral student.

University: Université de Rennes 1, France.

Source of funding: BecasChile (Conycit, Government of Chile).

Aim of the study: To advance the knowledge about family care received by dependent older adults in Chile.

If you decide to participate in this study, you will be asked to participate in two interviews (one at this time and another within the next few weeks). Each interview will last approximately one hour. If during the interviews you want to stop and continue at another time we can do it in an additional interview. The topic of the interviews will be your experience as a caretaker of your father / mother / father-in-law / mother-in-law. The interviews will be recorded, but they will be treated as confidential and anonymous. In addition, I will ask you to answer a brief questionnaire about your demographic characteristics and another to determine the degree of dependency of your parent / parent-in-law if you do not know. I will also take some pictures of you, they will only be published in the thesis document.

Possible risks for you: A possible physical or emotional tiredness by telling me about your experience as a caregiver.

Possible benefits: Relief from sharing your story with another person, better understanding your own experience as a caregiver.

Costs: The only cost is your time for interviews.

You may decide to stop participating in the study at any time.

Remember that all information will be kept confidential and your name will never be revealed.

I, ____ accept to participate in this study.

Date: __________________ Signature: _____________________

Appendix IV. Demographic characteristics and socioeconomic status of the caregiver questionnaire

This questionnaire was administered at the beginning of each interview with the main carers. Questionnaire time totalled around 10 minutes. The researcher conducting the interviews to the main carer administered the questionnaire.

As part of this research, I need to ask you a few questions about you and your family before we start with our conversation. Please let me know if you have any questions while I am asking you the questions and remember that this information is confidential.

How old are you? __________

What is your marital status?

☐ Single ☐Married ☐ Widowed ☐Divorced or separated

What is you highest educational attainment?

____

Are you currently employed?

☐ Yes ☐ No

If you are employed, what is your working schedule?

☐ Full time ☐ Part time

If you are employed, what position do you hold? ______________________________

Do you have children?

☐ Yes ☐ No

If you do have children, how many of them live with you? ______

How old are they?_____________________________

How many siblings do you have?

_____brothers _____ sisters

In the case you do have siblings, which position do you have among them?

☐ The youngest ☐ In the middle

☐ The eldest

Who lives with you in your household?

☐Partner ☐ Children

☐Mother ☐Father

☐Mother in law ☐Father in law

☐Siblings ☐Siblings in law

☐Other relative ☐Other persons

In the case you don’t live with the elderly you care,

How far do you live from her/him? ________ minutes by bus /car/walking

Who lives with the elderly? ___________________________________

How long have you been the main carer of the elderly? ________ months

Regarding the elderly for whom you provide care,

How old is she/he? ________

What is her/his educational attainment?

____

What is his/her marital status?

☐ Single ☐Married ☐ Widowed ☐Divorced or separated

Do you know his/her dependency level?

☐Low ☐Moderate ☐Severe

☐Unknown (in this case, conduct the Barthel index)

How many children does the elderly have?

_____ sons ______ daughters

Where do they live today?

____

____

____

The following questions are to determine the socioeconomic status of the caregiver’s household. Answers to questions 1 and 2 are combined in the matrix below.

1. What is the highest level of educational attainment of the head of the household?

☐ No studies
☐ Incomplete primary
☐ Complete primary
☐ Incomplete secondary
☐ Complete secondary
☐ Incomplete technical or vocational

☐ Complete technical or vocational secondary
☐ Incomplete university
☐ Complete university

2. Could you please tell me which of the following items or services you have at home?

☐ Hot water access
☐ Colour T.V
☐ Refrigerator
☐ Washing machine
☐ Domestic service
☐ Microwave
☐ Cable or satellite T.V
☐ Computer
☐ Internet
☐ Vehicle

Household socioeconomic status matrix

		Sum of the number of items in the household (q2)										
		0	1	2	3	4	5	6	7	8	9	10
Educational attainment of the household head (q1)	No studies	L	L	L	L	L	ML	ML	ML	ML	M	M
	Incomplete primary	L	L	L	L	L	ML	ML	ML	M	M	M
	Complete primary	L	L	ML	ML	ML	ML	ML	M	M	M	M
	Incomplete secondary	ML	ML	ML	ML	ML	ML	ML	M	M	M	HM
	Complete secondary	ML	ML	ML	ML	M	M	M	M	HM	HM	HM
	Incomplete technical or vocational	M	M	M	M	M	HM	HM	HM	HM	HM	H
	Complete technical or vocational or incomplete university	M	M	M	M	M	HM	HM	HM	HM	H	H
	Complete university	M	M	M	M	M	HM	HM	HM	H	H	H

Note: L_ Low, ML: Medium-low, M: Medium, HM: Medium-high; H: High.
Source: Adimark (2015), *Modelo Estimativo del N.S.E en los hogares de Chile*. Santiago: Adimark.
Available at: http://www.adimark.cl/medios/estudios/mapa_socioeconomico_de_chile.pdf

Appendix V. The Barthel index

Note: A Spanish version of this questionnaire was applied to the caregiver (daughter / son / daughter-in-law) before the beginning of the interview to identify the level of dependence of his / her father / mother / father-in-law / mother-in-law if this level was unknown. In most cases, main caregivers were aware of the level of dependency of the elderly as it is measured in the primary health centres' yearly preventive medicine examination.

For each of the following activities, please tell me the level of dependency of your elderly parent / parent-in-law:

Activity **Score**

FEEDING

0 = unable

5 = needs help cutting, spreading butter, etc., or requires modified diet

10 = independent ______

BATHING

0 = dependent

5 = independent (or in shower) ______

GROOMING

0 = needs to help with personal care

5 = independent face/hair/teeth/shaving (implements provided) ______

DRESSING

0 = dependent

5 = needs help but can do about half unaided

10 = independent (including buttons, zips, laces, etc.) ______

BOWELS

0 = incontinent (or needs to be given enemas)

5 = occasional accident

10 = continent ______

BLADDER

0 = incontinent, or catheterized and unable to manage alone

5 = occasional accident

10 = continent ______

TOILET USE

0 = dependent

5 = needs some help, but can do something alone

10 = independent (on and off, dressing, wiping) ______

TRANSFERS (BED TO CHAIR AND BACK)

0 = unable, no sitting balance

5 = major help (one or two people, physical), can sit

10 = minor help (verbal or physical)

15 = independent ______

MOBILITY (ON LEVEL SURFACES)

0 = immobile or < 50 yards

5 = wheelchair independent, including corners, > 50 yards

10 = walks with help of one person (verbal or physical) > 50 yards

15 = independent (but may use any aid; for example, stick) > 50 yards ______

STAIRS

0 = unable

5 = needs help (verbal, physical, carrying aid)

10 = independent ______

TOTAL (0–100): ______

Severe dependency: <59 points

Moderate dependency level 60-80 points

Low dependency 80-100

Appendix VI. Carers' sociodemographic characteristics

Name	Age	Socio economic level	Relationship with elderly	Work status (outside elderly care)	Other caring demands	Dependency level of the elderly	Support received	Living arrangement
Adela	58	Medium	Daughter	Working	No	Severe	Paid carer from 8h30 to 19h	Co-residence
Alejandra	45	Medium	Daughter	Not working	No	Severe	Husband and mother	Non-co-residency
Ana María	62	High	Daughter	Not working	No	Moderate	Formal care in residence	Non-co-residency
Andrea	48	Medium	Daughter in law	Not working	Children in school age	Moderate	Husband and daughter	Co-residence
Antonia	61	Medium	Daughter	Retired	No	Severe	None	Co-residence
Aurora	59	High	Daughter	Working	No	Severe	Formal and brother	Non-co-residency
Bernardita	53	Low medium	Daughter	Working	No	Moderate	No	Co-residence
Blanca	78	Medium	Daughter	Not working	No	Severe	No	Co-residence
Carmen	63	Low medium	Daughter	Working	Yes, her grandchildren	Severe	Sisters	Co-residence
Catalina	59	High	Daughter	Part time	No	Severe	Sister	Co-residence
Cintia	65	Low medium	Daughter in law	Retired	No	Severe	Formal care in elderly residence	Non-co-residency
Claudia	60	Medium	Daughter	Working	No	Low	None	Non-co-residency
Colomba	36	High	Daughter	Working	No	Low	Brother and paid carer	Co-residence
Consuelo	52	Medium high	Daughter in law	Working	Children in school age	Severe (mother-in-law) and moderate (father-in-law)	Paid carer, from 8h to 17h	Co-residence
Elisa	48	High	Daughter in law	Not working	Children in school age	Low	Paid carer, day and night	Co-residence
Estela	62	Medium high	Daughter	Retired	No	Moderate	Paid carer from 9h to 13h	Co-residence
Eugenia	56	Medium	Daughter	Not working	No	Severe	None	Co-residence
Fátima	46	Medium	Daughter	Not working	Children in school age	Moderate	Sometimes husband and children	Co-residence
Florencia	45	Medium	Daughter	Working	No	High	None	Co-residence
Francisca	42	Medium	Daughter	Working	Yes, her daughter	Low	None	Non-co-residency
Isabel	51	Low medium	Daughter	Not working	No	Severe (father) and moderate (mother)	None	Non-co-residency
Josefina	65	High	Daughter	Not working	No	Severe (mother) and moderate (father)	Formal and all siblings	Non-co-residency
Lucía	56	Low medium	Daughter	Working	Yes, her daughter	Moderate	None	Co-residence
Lucy	45	Low medium	Daughter	Working	No	Moderate (mother) severe (father)	Her son	Co-residence

María	50	Low Medium	Daughter	Not working	No	Moderate	Sometimes husband	Co-residence
Marita	79	High	Daughter	Retired	No	Severe	Formal	Co-residence
Mauricio	54	Low medium	Son	Not working	Yes, her sister	Moderate	None	Co-residence
Ofelia	59	Medium	Daughter	Working	No	Moderate	Sister and paid carer	Non-co-residency
Paula	54	Low medium	Daughter	Working	No	Low	Siblings	Co-residence
Paz	54	Low Medium	Daughter in law	Working	Sometimes grandchildren	Severe	Husband	Co-residence
Pedro	58	Medium high	Son	Working	No	Severe	Sisters and paid carer	Co-residence
Penélope	50	Medium high	Daughter	Working	No	Moderate (mother) and moderate (father)	Sister and paid carer	Non-co-residency
Pilar	61	Medium	Daughter	Not working	No	Moderate	Sister	Non-co-residency
Rebeca	61	High	Daughter	Retired	No	Moderate	Sisters and professionals	Non-co-residence
Rita	55	Middle	Daughter	Not working	No	Severe	None	Co-residence
Rodrigo	70	Medium	Son	Retired	No	Moderate	Sometimes son	Co-residence
Sandra	42	Low medium	Daughter	Not working	Children in school age	Severe	No	Co-residence
Sara	53	Medium	Daughter	Working	No	Moderate	Sometimes husband and children	Co-residence
Silvia	49	Low medium	Daughter	Not working	No	Severe	No	Co-residence
Trinidad	62	Medium	Daughter	Retired	Her brother and sometimes her grandchildren	Severe	Paid carer from 9h to 13h	Non-co-residency
Victoria	45	Low medium	Daughter in law	Not working	Children in school age	Moderate	No	Co-residence
Violeta	62	Medium	Daughter	Retired	No	Moderate	None	Co-residence

Appendix VII. Caregiver profiles

1. Adela

Adela is the main carer of her mother with Alzheimer's disease. She has been caring for her mother for five years. Adela has four brothers but none help with care. Adela works full time and during the day a male neighbour cares for her mother under a paid arrangement. She fears this man will quit because her mother's dependency is increasing and the man does not provide intimate care. Adela thinks she might need to quit her job, but she wouldn't like to. Adela took the decision to be her mother's carer because she knew no one else would do it and, as she emphasises, she is her mother. Adela has a partner and they live apart. Her only son lives in the south of Chile. She visits him once a year and takes her mother with her when visiting him. Adela would like that her brothers helped her at least one week a year so she can take vacations with her partner. For the five years she has been the carer, she has only gone for vacation to places where she can take her mother.

Every day, before going to work, Adela puts a diaper on her mother. Her mother stays with the same diaper the whole day, so that the male carer does not need to change it. When Adela comes home at 19h she takes out the diaper and gives her a bath. For the last few weeks, Adela's mother has started to pull out her diapers. It has become a problematic situation, to the point that Adela is thinking about quitting the job she likes and needs if she does not find a trustful woman who can take care of her mother during the day.

Adela is tired and feels constrained in the things she can do because of the care arrangement. Before her mother's dementia, Adela and her mother always had a difficult relationship. Her mother lived close to the beach, two hours from Santiago. Adela barely visited her. Her mother had a difficult character and Adela lacked the patience to be close to her.

Adela appreciates, however, the opportunity to be her mother's carer and reconstruct their past relationship. Her mother has a completely different personality than she had when she did not have dementia. For Adela, caring is an opportunity to get along with her mother and become closer after a long history of distance. Dealing with her mother now that she has changed her personality is not a difficult task. The new relationship they are constructing and how Adela perceives it, have helped her to experience her mother's care with a sense of fulfilment and satisfaction, despite the difficulties she faces.

The entrance hall to Adela's apartment has the unpacked grocery bags she didn't have the time to put away when she came back from work. All windows were open. Her mother had taken her diapers off and defecated all throughout the apartment. Adela dropped everything to clean up quickly before the smell became stronger. The male carer that looks after her mother when Adela is at work does not provide intimate care. He didn't know what to do when she took off her diapers and decided to just leave the elderly woman for Adela to take care of the situation when she came back. Adela arrived, exhausted after shopping for groceries, a full day of work and a one and a half hour commute. Though grocery bags were still in the entrance hall, Adela was able to manage the chaos before the interview. She looks tired. For the interview, her mother was clean and in her pyjamas.

2. Alejandra

Alejandra is 45 years old and the youngest daughter of an elderly couple. She is the main caregiver of her cognitively dependent father. She lives with her husband in the same city as the elderly couple but in a different municipality, a 40-minute car-ride away. Despite the distance, she visits her parents' on a daily basis; her husband drops her off at her parents' place every morning when he goes to work. Her two siblings are men. One of her brothers lives with the elderly couple. She receives support from her mother and her husband. They come from a middle-income family.

Alejandra found it hard to accept her father's cognitive deterioration and denied it at first. She preferred to think nothing was happening, until acceptance was inevitable. Alejandra has always had a positive relationship with her parents and was specially closed to her father.

Alejandra's relationship with the brother that co-habits with the elderly couple is complicated. They have never been particularly close but now that the family dynamics hava changed due to her father's dependency, their relationship has become more difficult. Alejandra complains that her brother does not cooperate at all, that he shows no interest in their parents' care and that he lives off the elderly couple's pensions. She argues that the only thing does is go to his parents' house to eat and sleep. Her brother is involved in a religious community and, according to Alejandra he has lost his head; she is not sure if it's a religious community or a sect.

She has a very good relationship with her husband, who provides strong support with the elderly care. She feels her parents' loves her husband; they consider him as third son. Alejandra has been going through a hard time with her husband because they have been told that they won't be able to have children. Besides the pain that has caused, Alejandra thinks that this difficulty has made the couple stronger, and that's the reason why they support each other with the elderly care.

Alejandra is eager to find a part-time job that would allow her to spend some time with her elderly parent while at the same time earn some money. She used to work full-time as a salesperson for a large retailer. She quit when her father began showing signs of dementia and her employer did not change her to change to a part-time contract. She would love to be able to combine her caring duties with paid employment, but it hasn't been that easy to find a flexible or part-time job. She experiences this situation as a big constraint.

Alejandra participates in an elderly care programme run by the primary health centre. It is mostly and informational programme on providing care for a dependent elderly and for herself. Alejandra's father was diagnosed with dementia two months ago, so she considers the information she receives as valuable. Since her father's diagnosis Alejandra -and sometimes her husband- has participated in a municipal programme for carers of elderlies with cognitive dependency, *Cuidando al Cuidador* (Caring for the Carer). Professionals from a mental health outpatient community centre (COSAM) support and complement the community's primary health care centre efforts.

At the moment of the interview, which was conducted in her parents' place, Alejandra showed vivid emotions towards their situation. She was particularly sad with her father's diagnosis and had difficulty accepting he will no longer be the same. The negative relationship she has with one of her brothers is a matter of concern and daily pressure. The difficulty finding a part-time employment affects Alejandra's desire of economic independency, makes it harder for her to accept her caregiving role and frustrates her, adding to her feelings of pressure.

3. Ana María

Ana María is 62 years old. She is the main carer of her elderly mother who lives in an expensive nursing home. Of her four siblings, Ana María is the only who lives in Santiago (her brothers live in the South of Chile, her sister in the United States). Ana María's sister comes every summer for a month to give Ana María some respite. Ana María is satisfied with her sister's support and has a good relationship with her. As a result, she is in charge of all the organisation and management tasks for her mother's care. She has four daughters, one son and twelve grandchildren. Anytime one of her daughters has a problem with their children care arrangements Ana María is there to help. For Ana María, having multiple care roles is a constraint. Coming from a high-income family, having multiple care responsibilities means that she doesn't have free time to keep her social life as it was before.

Ana María visits her mother every other day. She organises her medical appointments and buys her medicines and all she needs (e.g. clothes). She would appreciate if her daughters would visit her mother so she wouldn't have to as often and would have more time for herself. However, she does not receive this support from her daughters, nor she asks for it.

Ana María feels absorbed by her mother's care. Every time Ana María leaves her mother says: "Are you leaving already?" Ana María feels bad and angry. When her father died, four years ago, her mother started feeling lonely and requesting more company from her children, especially from Ana María. For Ana María, feeling absorbed by the relationship with her mother, makes her experience care intensively. Elderly care is atrocious for the children, says Ana María when describing her care experience. Despite this pressure, she would never abandon her role. Ana María's economic condition allows her to externalise all personal care tasks that her mother needs. Still, she recognises that the work she does managing and organising her mother's care should be paid by the rest of her siblings. She is using her time; she has postponed many of her personal activities and spends money on the weekly psychological treatment she receives since becoming her mother's carer. For her, her mother's care is a shared responsibility, not exclusively her own. Ana María met with her brothers and her husband a week before this study's interview to discuss issues related to the family's agricultural business. Ana María's husband took the opportunity to tell Ana María's brothers that she deserved a salary for their mother's care work. Ana María felt embarrassed while her husband brought up the issue. They did not react favourably; they found it ridiculous. The issue was not discussed again and Ana María regrets having talked about it.

She has been a housewife since she got married. After finishing school, she studied landscape design and has had sporadic jobs as a garden designer, but her priority has been to raise her children. When Ana María refers to her husband she highlights he is an intelligent man, with a good career, but that his role is only one of a breadwinner and nothing else. She carried with the responsibility of caring for the dependent members of the family, postponing her professional career. She finds that this arrangement is not fair and would not like to see the pattern repeated in her daughters' lives. For her, it is a priority that her daughters work and progress in their professional careers. This is why she cares for her grandchildren as well.

Ana María notices that her husband does not provide any support other than financial support. She does not justify his lack of support. She feels uncomfortable with the traditional breadwinner model. Ana María is aware of gender inequality in the provision of care, especially in her generation.

Ana María remembers her mother as a very intelligent and independent woman, and that image makes Ana María sad today, as her elderly mother is cognitively dependent and physically frail. In 2008, her mother had a stroke and began losing her cognitive capacity. Her father was also sick with a kidney disease that required daily dialysis at home. They were under the direct care of two nurses, and Ana María visited every other week to organise their care. In 2010, Ana María's father died and her mother's health deteriorated and required Ana María to be closer. Her mother would call her by phone requiring her to visit or would claim there was an emergency for her to come. She just wanted Ana María to be close to her. Ana María would have to drive five hours to reach her (before living in the nursing home, Ana María's mother lived in San Rodrigo where several of Ana María's brothers live). Ana María decided to have her mother live in an elderly institution. Ana María had a hard time at first. She felt guilty of not taking her mother to live with her. Now that the elderly lives in a nursing home in Santiago, she has become even more attached to Ana María who is the only one that visits her often. Today she is convinced that it is the best arrangement for both of them.

For Ana María, her mother's care is a shared responsibility, not exclusively her own. She feels sad and angry for her brothers' lack of comprehension and support. Their relationship got damaged increasing the frustration Ana María feels towards her care experience. The situation with her brothers has eroded the relation she now has with her mother.

4. Andrea

Andrea a 40 year-old woman from a middle-income household, is the main carer for her mother-in-law and her aunt-in-law. Both elderlies have severe cognitive dependency; they both have been diagnosed with Alzheimer's disease. Andrea is also the main carer for her six-month-old granddaughter. She does not have paid employment. Andrea lives with the two elderly in a beautiful and old and well-preserved house in downtown Santiago (the house belongs to Andreas's mother-in-law's family). Andrea's husband, her two daughters (one is 21 years old and the other, 16 years old) and her baby granddaughter also live in the house.Andrea's husband works from home staining glass and actively participates in the caring tasks.

Andrea is very grateful to her mother-in-law to Andrea is grateful to her mother-in-law to be able to live in that house where she has raised her two daughters. This gratefulness makes reduces the pressure of her experience as caregiver.

Andrea has been caring for her mother-in-law and aunt-in-law for eight years. Andrea has only recently found time for herself. With her time, she is able to occasionally see friends and to finish secondary school by enrolling in night programme. She plans to continue and enrol in post-secondary education. Her educational project stumbled when her 16-year-old daughter got pregnant. Andrea and her husband felt sad and guilty. They thought had put their daughters aside in engaging too much with elderly care. Andrea decided to become her granddaughter's main carer so that her daughter could continue school, finish her studies and go to university. Andrea gave up the little free time she had and her dream of a university degree. She preferred giving her daughter the opportunity to go to university and getting a well-paid job. Knowing that her daughter has a bright future ahead of her compensates for her own postponement and tiredness.

Offering her daughter this possibility is a sensitive issue for Andrea. She did not finish secondary school as a teenager because she married and had her first daughter at a young age. She has experienced the lack of opportunities that resulted from being a full-time caregiver and from not finishing secondary education. She does not want the same future for her daughters. She taken up all her granddaughters childcare responsibilities; she will do it as long as necessary so that her daughter can have a profession and access good quality employment.

Her husband participates actively in the care arrangement. She has only one brother-in-law (no sisters-in-law). Andrea does not expect her brother-in-law to provide direct care for his mother or aunt. She neither expects financial support from her brother-in-law because the elderlies' pensions and past savings can cover the care expenses. Andrea does not feel she should be compensated for the care work she does; she feels she receives compensation by living in the elderlies' house which has been a resource to raise her own daughters there. Andrea and her husband would like that her brother-in-law provides emotional support to them and emotional care to the elderlies, none of which he does. He only visits the elderlies once or twice a year. As Andreas's expectations towards her brother-in-law's participation in elderly care are low, they are easy to fulfil, or of less importance, diminishing the potential conflict.

Two interviews were conducted with her. The first one was in presence of her husband, elderly women and granddaughter. The second interview was conducted with only her, under the shadow of a tree in her backyard. Her husbands was caring for the elderly women and the baby was taking a nap during the second interview.

5. Antonia

Antonia is 61 years old, she comes from a middle-income household. and the main carer of her severely dependent 98-year-old mother. Her father died 30 years ago, her sister twenty years ago. She does not have any children. She has always lived with her mother, who now has a cognitive dependency. Antonia cannot communicate with her. Antonia is fully dedicated to her mother's care, she is her mother's only child and receives no help from other people for her mother's care. The impossibility of communicating with her mother is experienced as a difficulty for Antonia. In the past, they did not get along well. Antonia thinks her late sister got married to rebel, leave the house and escape from her mother. Antonia couldn't. Her personality was weaker, she was more introverted and timid.

She remembers her mother as a very protective, authoritarian mother; she was not nice to Antonia and was not available when Antonia needed her. When Antonia was a girl, her mother wouldn't allow her to leave out of the house to play with neighbours. When Antonia was an adult, her mother always asked where she was going. Whenever Antonia went to church, her mother said that she should better take her bed and sleep there. Antonia now regrets being so lonely and isolated. She blames her mother for it. Antonia was an independent dressmaker. She stopped working five years ago when her mother's mental health began deteriorating and she didn't have enough time to meet her mother's care demands. She lives in a municipality that does not provide social support for elderly care. It is a constraint for her. She sees the difference this kind of support can make in carers' experience. Two of her friends are sisters caring for their cognitively dependent parents, but, as opposed to her, they live in a municipality that provides support. Antonia says the availability of this support is one of the reasons why their experience is better than hers.

Antonia experiences caregiving with a high degree of pressure. Her religious community offers her only source of support. Antonia recognizes that only her faith in God and her religious beliefs keep her by her mother's side, caring for her.

Antonia struggles, she feels overwhelmed; she is depressed and isolated. She gets angry and has anger issues from issues she and her mother never solved. Antonia regrets her life, but she keeps going as her mother's carer because she feels a moral obligation. She wants to pay her mother back, it's what, according to her religious norms, a daughter should do. She wouldn't want her children to follow her example, in the hypothetical case she did have children.

Antonia's house is full of things. She keeps objects everywhere. Things that she finds on the street. Things that she gets from neighbours. Things that she has bought. She doesn't use them; she never gets rid of them. She keeps them, wherever they fit. Her accumulation of things parallels the bad feelings she has accumulated due to the historically bad relation with her mother.

Although Antonia tries to forgive her mother because she had, herself a difficult childhood and adult life, Antonia cannot break away from all the anger she has accumulated. She would like to run away, but her moral obligation keeps her caring for her mother. She sleeps long hours; she cries a large part of the time she is awake and watches television to disconnect.

The fact that Antonia’s mother has Alzheimer’s disease complicates their relationship even further. It makes it difficult for Antonia to re-establish a new relationship with her mother and overcomes their past difficulties.

6. Aurora

Aurora is 59 years old and cares for her severely dependent mother. She comes from a high-income household. She works from home as the family's construction company's accountant. Aurora's mother lives in her own place with a nurse and a maid. Aurora manages her mother's care, including all domestic issues, which were under her mother's responsibility until she lost her physical autonomy three years ago. The mother's savings and the pension she receives from her late husband since are sufficient to pay for her living and care arrangements.

Aurora's mother lives a 25-minute drive away from her. Aurora visits her mother daily and spends most of the day at her mother's place. The 25-minute drive is stressful because of traffic.

Aurora has two married sons, they both have children. Aurora sees them once in a while on the weekends, she would like to see them often but she doesn't have the time to do so. Her husband lives in the north of Chile during the week days, there they have all the constructions they are working on and Aurora's husband has to be on the field to supervise them. Aurora is used to this arrangement, and now that she is dedicated to her mother care she likes the fact that she can be alone during nights and evenings so she can catch up on work without any disruption.

Aurora wakes up early every morning to get some work done. She then visits her mother, returning to her house in the afternoon or evening to have dinner and continue her working until late at night. Although her job's flexitime and flexiplace allows her to combine employment and care, it does not flow smoothly. For Aurora, it adds difficulty and is a source of fatigue. It is difficult for her to combine both works, she is extremely tired.

Aurora has four siblings; only one of them, a brother, shows interest in the elderly care issues and cooperates by managing finances. He also visits their mother at lunch time; Aurora sees him often and appreciates his presence. His brother's participation helps her overcome her feelings of loneliness.

She doesn't have much contact with the other siblings; she is mad at them for not participating in the care arrangement. All siblings used to have a better relationship in the past, but now that they all have their own families and grandchildren they seemed less and less worried about their elderly mother. Aurora gets furious when talking about the two siblings that do not participate in the care arrangement. She is especially mad at her only sister, although she knows her sister is dedicated to her elderly parents-in-law's care and barely has time for other issues. She would like her sister to be closer and share their mother's care.

Aurora's mother's health deterioration has been gradual and the elderly woman, who used to have a very strong character and was very independent, gets upset realising she is losing the control of her house and life. Aurora's mother is aware and upset that she is no longer managing the house. This upsets Aurora as well as her mother still wants to control all the aspects of the house. Though Aurora’s mother’s mental health has not deteriorated, she is completely dependent on a physical level. Her mental capabilities have made it hard for her to give up her responsibilities. This is distressing for Aurora and makes her sad.

Aurora and her mother have generally had a good relationship, they have never been too close but have always stayed in touch with one another. Aurora had a closer relationship with her father, who was a school teacher, a man loved by many because of his good character and kindness. Aurora misses him.

The interview was conducted in Aurora’s apartment at 9pm. We had the conversation in the dining room table. Her computer was on, next to folders and papers related to her job. Aurora was open to sharing her experience. The conversation flowed smoothly and lasted for one hour and thirty minutes.

7. Bernardita

Bernardita is 53 years old; she comes from a low-middle income household. She lives with her father and is his main caregiver. Bernardita's father has a low dependency. Bernardita was born and raised in Chile's rural South; she migrated to the capital city looking for job opportunities. When she settled, she had her parents join her. She has two sisters and two brothers; her mother died 15 years ago.

Bernardita maintains the household with his father's pension, which amounts to approximately 145 euros a month, and Bernardita's salary, which add another 100 euros. She used to work as cleaner for five days a week, but as her father's dependency increased she reduced her working hours to two days a week. For Bernardita, the most important part of having a paid job is receiving money; she is not pleased with having to work fewer hours. Though she values the fact that she is able to keep part of her job, her monthly earnings declined by 60%.

Bernardita's adapts her work on the basis of her father's health. She leaves her father alone for a couple of hours a day when she goes to work. Leaving him alone worries her. In addition the reduced working hours means a reduction in her salary. Dedicating herself to her father's care increased her financial constraint.

Care for her father lies exclusively on Bernardita; her sisters visit sporadically. One of the two brothers and both sisters help with money if extra costs with the elderly care arise (e.g. hospitalisations), but do not contribute on a regular basis. Bernardita became the main caregiver because she was the only single woman among her sisters. In her family, the women lived with their parents until they married. Her sisters moved out as they married. Ten years ago, her father had stomach cancer and Bernardita was the only woman in the house (her mother had already passed away five years earlier). She realized that she was going to be alone, unmarried, for the rest of her life as her sisters were married.

Bernardita decided not seek marriage and dedicated herself to caring for her father. It is a job that requires her constant attention and that has defined her current life and her future. She does not regret choosing celibacy for care, though every once in a while she looks at her married sisters and thinks about how different her life would have been with a family of her own, with a husband and children. Although she feels that being single and fully dedicated to her father's care was an explicit decision, she also feels it was an obligation that fell upon her, given that none of her sisters were available, and that she felt her father couldn't be left alone.

An informal job like Bernardita's offers her the flexibility to reduce working hours depending on her fathers care needs and at the same time continue working, but at the expense of much-needed earnings and income security. Besides the difficulties she faces when balancing care and paid work, the combination of paid work and care provides positive aspects for Bernardita' life as well, she enjoys getting out of the house for a while, see other things and faces, different from her house, her father and care related issues. Paid work offers Bernardita respite from her caring duties.

The first interview with Bernardita was conducted in a restaurant close to her place of work. The interview lasted one hour and a half and the interviewee was relaxed and open to sharing her experience. A second interview was conducted in her place a week later. This time her father was around all the time and Bernardita was nervous and less open than in the first interview.

8. Blanca

Blanca is 78 years old. She cares for her 102 year-old mother. They live in a middle-income household. Blanca has been caring for her mother for 25 years, since the onset of her dependency. For the last three years, Blanca's mother has severe dependency. Blanca provides most of her mother's care: she prepares food and feeds her, she washes her in her bed and changes her diapers, she dresses her, arranges appointments with doctors and health practitioners, etc.

Blanca is extremely tired and in physical pain due to advanced osteoarthritis, chronic back pain and the fact that she provides daily care to her mother alone, she does practically everything by herself. And indeed she looks very tired during our interview in the living room of her house. She looks old; so much that when I rang the doorbell and she opened the door I asked for Blanca thinking she was the elderly that Blanca was caring for.

Blanca has 5 brothers and 4 sisters. Blanca provides care because she is the only one available among the phratry. One sister used to help her with her mother's care but that sister is now severely sick with cancer disease. Once a week, Blanca's daughter comes to help her to change her mother's bed linens. Only one brother helps her with her mother's surveillance one Monday a month. This allows Blanca to go to the supermarket, to the primary health centre and pharmacy to get medicines and to the municipality to get her and her mother's pension. Blanca then comes back to give her mother food and medicines and to change her diapers. Blanca's brother does not provide direct care to her mother.

Blanca considers she has a positive relationship with all her sibling and they get together often at Blanca's place to spend time together (they play cards, have tea and chat). Though Blanca's siblings do not do not provide direct support with their mother's care, they do give Blanca moral support.

Blanca faces financial constraints and feels lonely. Although she struggles with her caring role, she feels the strong moral obligation to provide care. This obligation stems from her religion beliefs. The obligation is strong enough that she would never give up her role.

When Blanca needs respite she prays the rosary but she usually falls asleep while praying. Although her historical relationship with her mother was self-described as normal, caring for her mother has damaged their relation. Blanca confesses she sometimes gets mad and is mean to her mother. She says she screams to her mother when she refuses to eat, for example. Blanca says her mother gets angry when this happen and their relation spirals downwards. Her mother then tells whomever she sees (her son who visits her one Monday per month, for example) that Blanca is a bad carer, and Blanca gets even madder. Then Blanca feels guilty, feels the pressure increase and her experience becomes overwhelming.

9. Carmen

Carmen is 63 years old. She is the main carer of her severely dependent mother. Her mother is both cognitive and physically dependent. Carmen comes from a low middle-income household and decided to stop working to be fully dedicated to her mother's care.

She used to work as a cleaning lady when her mother moved in to live with her. As she no longer worked as a cleaner, she began caring for her two grandchildren as well while her daughter worked in exchange for some earnings (her daughter pays her for taking care of the children). She also accepted caring her grandchildren because she wants to support her daughter's professional career. One of Carmen's sisters visits her daily. She also cares for her own three grandchildren, and brings them in her visits. Between the two, they care for five children and their mother. Another sister also comes sometimes with her own grandchildren as well.

Carmen recognises to be tired at the end of the day and that the ideal situation for her would be to enjoy the presence of her grandchildren only once in a while, not being their main carer on a daily basis. Carmen's mother wakes up often during the nights, the old lady screams and Carmen wakes up often. She is tired. However, Carmen is fine with her role, she doesn't imagine it to be different. She says her mother was a good mother and that she dedicated her life to her daughters. Carmen would never left her alone. Carmen would never choose a nursing home as an appropriate place for her mother's care. She believes they mistreat the elderly. Also, her family does not have the money to pay for a high quality nursing home.

Carmen is very concerned about her mother's health. The women is prostrated in a bed day and night, she is very thin and barely eats. She wishes her mother would die to stop suffering, but the thought of her death makes her sad. Carmen cries when talking about this.

Her mother moved in when she started needing care. Cohabitation brought a major change in Carmen's nuclear family's life. At home, there is now her mother and during the day her sisters and the grandchildren. Carmen likes her sisters' presence and support, and values positively the fact of spending her mother's final years with her. However, she sometimes feels the pressure of the cohabitation situation when her husband says he feels invaded with the house full of people all the time.

The interviews were conducted at her place, in the second floor of the house, in a corridor next to her mother's room. There was noise from children coming from the first floor, they were Carmen's and her sisters' grandchildren. Her sisters looked in good humour and as if they all have a positive relationship.

10. Catalina

Catalina comes from a middle-high income household. She is a 55-year-old single woman and the main carer for her elderly mother with whom she lives. Her mother has a cognitive and physical dependency. Catalina has no children.

Catalina works as a secretary, weekdays from 9h to 13h. While Catalina is at work, her sister, who recently moved in to live with them after a divorce, stays with her mother. When she arrives home at 13h, Catalina is completely in charge of her mother's care and all household issues. For her, the most important aspect of having a paid employment is the chance to get out of the house and be immersed in a different atmosphere; respite from the difficult conditions she faces.

She has two sisters and three brothers. One sister, Fernanda, is very involved in her mother's care, she is the one currently living with Catalina and her mother. Catalina provides routine help to her mother. Fernanda offers back up help. Alexander offers circumscribed help by giving money for his mother's care. The twin brothers offer sporadic support, they do not live in the same city and they come once in a while to Santiago and visit their elderly mother.

Grace, the eldest sister, is not involved at all. Catalina has been able to keep a good relationship with Grace despite her lack of involvement, because she understands Grace's reasons for being far from her mother. Catalina was born when Polio disease was eradicated from Chile, but she was one of the last cases of incidence of the disease. Given her disease, her parents' attention when their children were young was directed almost exclusively at Catalina, leaving the rest of the siblings to fend off by themselves or be under Grace's care. Catalina greatly values her parents' dedication to her. Catalina recognises that her mother was particularly mean to Grace during their childhood.

It is for this historical reason that Catalina is the main carer. Catalina finds the situation fair enough. Catalina maintains a good relationship with her sisters even though they do not participate as actively or at all in the care arrangement. Given the family history, she doesn't expect a different involvement in the care arrangement by the part of their brothers or sisters.

The interview was conducted in Catalina's apartment. She was nice and open. She looked more relaxed and resigned (in a positive way) with her role as carer when compared to other cases in the study, although her life was and is taught. While we were having the conversation her mother was in her bedroom watching television with the volume very loud.

11. Cintia

Cintia is 65 years old and is her mother-in-law's main caregiver. Her mother-in-law lives in a nursing home. Cintia is retired. Cintia has a husband, who is an only child, and two brothers. Cintia visits her mother-in-law every day (or every other day if she has something else to do). She provides mainly emotional support to her mother-in-law.

For 20 years, Cintia cared for her severely dependent mother. In caring for her mother, Cintia paid an external carer to provide care during the day on weekdays. On the 14th year, Cintia had to take a year of leave without pay from her work because her mother was increasingly frail and no external carer was willing to care for her, given the salary Cintia could pay. She was then able to find a place for her mother in a nursing home sponsored by the Catholic Church. She thanks God for the chance to leave her mother in a nursing home sponsored by the Catholic Church.

Cintia is comfortable with her mother-in-law's care arrangement and her role as an emotional support provider. She enjoys going to the nursing home and chat with the staff members, whom she knows for more than ten years as her own mother also lived in this nursing home. As Cintia is retired, she doesn't feel time pressured to get to the nursing home; she doesn't feel she doesn't have enough time to spend there, as she felt when her mother was there.

At first, the idea of leaving her mother in an institution was scary because nursing homes for the elderly, especially those available for low-income people, do not have a reputation for providing good quality of care to the elderly. She took a few weeks off of work and spent the time working as a volunteer in an elderly nursing home close to her house that was recommended by two of her colleagues, to see the elderly care conditions in place. She was pleasantly surprised with the living conditions of the elderly people and took her mother there.

When her mother-in-law was diagnosed with Alzheimer's, Cintia and her husband decided to take her to the same nursing home.

Cintia has a positive relationship with her husband. She has always gotten along well with her mother-in-law. Her husband is the only child so Cintia was the only woman available to be her main carer. She doesn't complain about her role as a carer. She would like to live in that same nursing home when she becomes elderly and dependent. She knows she would be well cared there.

The interview was conducted in the nursing home. People were friendly at her, they all say hi and ask about her mother in law's health. Cintia looked relaxed and happy.

12. Claudia

Claudia is 60 years old; she is married and lives alone with her husband. They have two children who live independently. She works part-time as a cleaner. Her 86-year-old mother has a recently developed a dependency which remains low. Claudia's mother lives alone in a different municipality, an hour and a half away from Claudia by public transportation.

Claudia belongs to a middle-income family, her husband's income is the main source of income in the family. Nonetheless, Claudia's earnings are very important to the household and to maintain the couple's living standards. She doesn't know what will happen with her job in a future in which her mother needs more care. Such a situation scares her.

Claudia's mother has been single for more than 30 years ago. Claudia's father abandoned her and her seven children. Claudia's mother can still do most daily activities by herself. She needs help cleaning the house, taking some medicines, managing her money and visiting the doctor, among other similar tasks. Claudia visits her mother at least four times a week; she takes her to the doctor whenever necessary and goes to her mother's place again if her mother needs help.

Claudia and her mother have always had a positive relationship. Their relationship has reversed now that Claudia's mother has become dependent. It is Claudia who helps her mother now. The reversal makes Claudia sad and uncomfortable. Before becoming her mother's carer, Claudia, already in her 50's, always felt like her mother's child, and enjoyed being supported and cared for as a child. Today, the 86 year-old-mother has become the daughter of their relationship, which disturbs Claudia deeply as she is not used to treating her mother like a daughter.

Claudia has always had a positive relationship with her husband, but lately they have had some disputes because, as she says, he claims she is too invested in her mother's care. He further claims that Claudia's role as the main caregiver is not fair Claudia has six siblings. He argues Claudia shouldn't take the whole responsibility on her shoulders. Though there are disputes (they have never scaled up), Claudia does not want to reduce her investment in her mother's care. Care, for her, responds to the historical relationship she has had with her mother. It responds to the love she has for her mother. Claudia is deeply convinced of her caring role. Her conviction allows her to better tolerate the disputes she now has with her husband and her siblings' lack of involvement.

If her siblings do not cooperate more in the future, she will still care for her mother. She is willing to bring her mother to live with her and her husband, even though it will take her spousal relationship some time to re-adapt to her new role and the new arrangement.

Claudia participates in a religious community and actively practices the Roman Catholic faith. Religion and the religious community give her support and willingness to continue with her role as a main caregiver.

This interview lasted one hour and 10 minutes. It was conducted in Claudia’s place, no one else was at the place while the interview was done.

13. Colomba

Colomba is 36 years old, works as an architect, and is the main carer of her 84-year-old father who has a low level of dependency. She lives with him; she is single. She belongs to a high-income household and manages her father's medical appointments, takes him there and is in charge of the house they share. A cleaning lady comes three times a week to help her with household chores. For most of the time, her father stays alone while Colomba is at work. He has no need to be accompanied at all times because he is autonomous for most basic daily activities.

Colomba has one brother. They are close and have a positive relationship. Her brother visits her father two or three times a week after his job to offer emotional support. He cooperates economically with his father's care and is also attentive to Colomba's needs, her situation and anything she might need. He is married and has a daughter; he is planning in moving closer to Colomba and their father so they can see each other more often and he can be be more involved in their elderly father's care.

Colomba decided to come and live with his father four years ago, when her mother died. As an architect, she renovated the house and now she is comfortable and happy in the house.

Colomba works as a landscape architect and loves her job. She doesn't have flexible hours or a flexible place for work. Being her father's main carer doesn't hinder her possibility to find fulfilment in her job. The example laid out by her mother is important. Colomba's mother loved her job as a University professor when she cared for her children; she enjoyed both roles of being a carer and a worker. She has no problem balancing care and paid work because landscaping is what she always wanted to do.

Colomba enjoys the personal fulfilment landscaping offers her. It causes no conflict as her father has a low level of dependency and she receives the support of her brother and an external carer three times a week.

Colomba is practically the only case in which a brother gives this kind of support to the caregiving sister. Colomba recognises gender is not a source of care-related inequalities in her family because among her parents there were never gender-related distinctions when it came to family or employment roles. Both her parents were university professors; they worked the same quantity of hours, earned the same salary and divided their children caring tasks equally. This is a unique situation, especially considering that Colomba's father is 84 years old and gender inequalities were stronger in older generations.

Colomba's mother died four years ago, and for Colomba the experience as her mother's main carer was by far more difficult than the experience she is having now with her father. It was particularly difficult and painful to Colomba to take in her mother's deterioration, her illness was faster and the dementia she had at the end changed her personality completely. For Colomba it was difficult to relate with her mother during that period. This time around, she is enjoying her time with her father. She likes cooking for him and having breakfast and dinner together, she appreciates the chats they have together, the time they spend watching the news in the television. She sees all those moments as an opportunity to spend the last years of her father's life together, a precious gift. She is somewhat worried about her father's future and about their financial situation, that's why she is currently saving money in case they will have to hire an external carer for more hours in the near future.

Colomba doesn't have a partner, and she says that in case she had, she would never take him/her to her place, she doesn't feel comfortable with the idea that her father sees her with partner. Colomba and her father have built a strong relationship that does not have space for any other person in her life.

Two interviews were conducted to Colomba, both at her workplace in a summer evening when not many people were around. The interviews were interesting and Colomba was eager to share her life, her family history and her experience as her father's carer.

14. Consuelo

Consuelo is 52 years old. She works part-time as a school secretary. She belongs to a high middle-income family. She is the main carer of both her parents-in-law. Her mother-in-law has severe physical and cognitive dependency and began her dependency path eight years ago. Her father-in-law has moderate physical dependency. Consuelo's husband is their only son, the elderly couple has two daughters.

Consuelo lives with both parents-in-law, her husband and her children. Three years ago, her mother-in-law had a cardiovascular accident that made her completely dependent. Her father-in-law became moderately dependent. Consuelo became their main carer. An external carer comes on weekdays from 8h30 to 18h.

Consuelo and her husband have been living with the now elderly couple for a long time and lived with them well before the onset of the elders' need for care. She married 30 years ago, and her parents-in-law offered them to live with them until they had the money to afford independent life. A couple of years later, Consuelo's children were born and they had the money to live independently. However, grandparents and grandchildren had gotten used to this conviviality and didn't want to be apart. Consuelo and her husband decided to stay. As the elderly begin to need help in daily life activities, Consuelo and her husband stayed in the elders' home, continuing the cohabitation. Elderly care costs are paid for form the elder's pensions and money coming from their three children (Consuelo's husband and her sisters-in-law).

Organisational and management tasks are the predominant tasks in her role as main carer. Organisation and management is overwhelming for her. On days when the external carer does not work (weekends and unforeseen absences), Consuelo coordinates with her sisters-in-law who provides care. It is particularly hard on unforeseen absences because Consuelo needs to a solution so she can go to work. Her sisters-in-law live in the same neighbourhood. They work part-time but they always have an excuse when Consuelo asks them to stay with the elderly.

Consuelo and her husband have the economic means to externalise part of the caring duties. She does not question whether they should have external. She neither questions whether it is appropriate to combine work with caregiving. She never mentioned mistrust on externalising care and did not feel guilty about not rendering care the whole day.

For Consuelo, the heaviest part of the caring experience is the lack of recognition from the extended family. If she would be able to go back in time and re-make the decision of becoming her parents-in-law's carer, she would decline. She finds care work receives little, if any, recognition from the rest of the family. She would appreciate her sisters–in-law expressing more gratitude and greater understanding over what she does. She would like her sisters-in-law and their children to be more involved as she thinks it would make a fairer arrangement. When the elderlies where healthy, their daughters and granddaughters visited them more often. It has been difficult to assume that their mother is severely dependent and they use it as an excuse for not visiting or helping more often.

The lack of support from their partner's phratry negatively affects her relationship with her siblings in law, and therefore, her care experience. Consuelo finds it unfair that her sisters-in-law excuse themselves from the arrangement on the grounds of emotional difficulty; it's not easy for any of them. She believes it's an obligation for their sisters-in-law to participate. Consuelo gets confused when trying to understand and explain why her sisters-in-law don't support the elderly care and when trying to understand her own feelings towards that lack of support. A year ago, Consuelo and her husband tried to organise care during weekends and holidays, when there is no external paid caregiver. They arranged a system of turns with each sibling providing care and sharing each period. It didn't work. Her sisters-in-law did not stay long enough during the day. Sometimes, when Consuelo's and her nuclear family had gone out of the city, they found the elderly couple were left alone in the house. A conflict with her sisters-in-law ensued. Though the system of sharing weekends continues, Consuelo knows that the elderly are alone a large part of the weekend, especially at nights, when Consuelo and her family are not in the house and a sister-in-law is supposed to be there.

Consuelo, unlike most carers in the study, mentions that her children provide strong support in the elders' care. Consuelo does not question the appropriateness of her children's support. Given that she became carer rather fortuitously, she believes care is not her own and sole obligation or she is the sole responsible for providing it.

15. Elisa

Elisa is 48 years old, from a high-income household. She is the main carer of her 87 year-old mother-in-law who has a low dependency level. Elisa also cares for her seven children, all of which are under 15 years of age. Her husband is an only child and she always knew that her mother-in-law would end up living with them and that she would become her caregiver. It is not her husband, the elderly's son, who adopts the carer role, because he is a man. She adopted the role because she is a women; she does not expect it to be any other way. She is also an only child and both her parents are still in good health. She doesn't want to think about what will happen when one or both her parents become dependent. In addition to her, her husband, her mother-in-law and her seven children, two women, under a paid arrangement, live in the house to provide support for household tasks and some of the elderly direct care. Elisa is proud to say that she knows the woman that helps with the direct elderly care tasks for 20 years. This woman takes care of Elisa's mother's personal needs 24 hours a day.

Elisa goes to church every morning once her children have left for school. This daily routine is like a therapy for her. It offers her a space to meet her friends, think about something different than her caring role and regain strength.

For Elisa, the organisation and management of care is the predominant activity in her role as carer. She sees it as one more responsibility in her caregiving agenda. Organising her mother-in-law's appointments with doctors and coordinating the help she receives from a paid carer is not a source of pressure. Organisational and management tasks are not a difficulty for Elisa.

Elisa is motivated to care as a form of safeguarding against her own future care. Though being her mother-in-law's main carer it is perhaps an obligation for Elisa, she accepted the role because she wants to set an example for her children. She would like to spend the final moments of her life surrounded by her children and under their care. She does not want "to be left alone somewhere". She thinks the best way to convey this personal desire to her children is by setting the example.

Historically, she has had a good relationship with her mother-in-law, which facilitated her accepting of her role. It allows her to experience care with a lower feeling of pressure. She recalls that when she dated her husband, her mother-in-law was very motivated by their relationship. Her mother-in-law always took her side when Elisa and her now-husband had minor disputes in front of her.

Elisa's motivation to careis partly the result of the good relationship with her mother-in-law, with her husband, and with her children, as well as with the match between her ideals of what appropriate care is and her mother-in-law's current care arrangement.

16. Estela

Estela is 62 years old. For 33 years, she worked as a teacher. She is an only child, a single woman and doesn't have children. She has always lived with her parents. Her father died twenty years ago, her mother, who is under Estela's care, is 98 years old and was diagnosed with Alzheimer's disease. Estela has been caring for her mother for the past fifteen years. Estela's retirement from teaching coincided with the time her mother began needing help with daily activities.

Estela and her mother live together in a middle-income neighbourhood house. They belong to a high-medium income household. Estela's father had a son from a previous marriage. Today, her half brother lives in the same neighbourhood and his wife, Estela's half-sister-in-law, helps Estela with her elderly mother's care during the mornings under a paid arrangement. Estela and her half-sister-in-law have a good relationship. Estela is worried because her half-sister-in-law is getting older herself and might not be able to continue helping Estela. She doesn't know how she will replace her, she does not trust any other external caregiver. Give the bad reputation of nursing homes, Estela refuses that option for her mother's care and for her own future care.

While her half-sister-in-law cares for her mother, Estela runs errands and goes for a soft one-hour run at a nearby park. This routine keeps her in a good mood and health. Weather permitting, she takes her mother to the park. There, Estela meets a friend who is also the main carer of her elderly mother with Alzheimer's disease. Estela considers this daily routine and social contact as therapy. In winter, as it is too cold to meet in the park, her friend sometimes comes over to her place with her mother. It is easier for them to meet at Estela's house as it offers enough space for two wheelchairs.

Estela and her mother have always had a positive relationship. She refuses the idea of a nursing home for her elderly mother's care. She refuses based on a bad experience from a neighbour whose mother is in a nursing home. The neighbour decided to take her mother out of the nursing home because she was almost dying due to the bad quality of the care she received. The neighbour found her mother in miserable conditions, full of bruises and extremely thin. Estela feels she cannot do that to her own mother.

Estela is single. She has no children. She is scared about her own future as a dependent elderly. Her future care anguishes her, she fears ending in a nursing home. As an elder, she would like to be in her own place cared for by a paid but trustworthy caregiver. She still fears being mistreated by an external carer.

One interview was conducted to her. The conversation took place in her living room. A dog was at the place at the same time. At the end I met her mother, an elegant women in a wheel chair. We couldn't establish a conversation due to her cognitive condition.

17. Eugenia

Eugenia is 56 years old and the mother of two grown-up children. She comes from a middle-income household, she has one sister and is the main carer of her severely dependent mother who lives with her. Her husband and their two children live in the house as well. The elderly woman has been severely dependent for seven years now.

Eugenia provides all the direct care for her elderly mother; Eugenia also carries out the managerial tasks. She has a weak social network and receives scarce social support. Eugenia only talks to one person about the problems and feelings related to her caregiving role: her daughter. Her daughter provides emotional support.

Eugenia is always vigilant of her severely dependent mother at home, even if she is not providing direct care. When she is doing something else she is still paying attention. On the rare occasions she leaves the house, she becomes concerned because she cannot keep an eye on her mother. Eugenia finds respite doing housework. Eugenia experiences mixed-feelings towards her situation. She recognises she does not have time for herself, but at the same time, she doesn't want her mother to leave her. She cried many times during the interview.

Before becoming her mother's main carer, Eugenia was a stay-at-home mom. She cared for her children until they were 18, starting when her first daughter was born, 23 years ago. She regrets leaving her children aside when she became her mother's caregiver. She is sad when she thinks about missing their children's last stages of their schooling. Now that they are independent, she regrets having missed part of their adolescence.

She admits she would like to work for at least a couple of hours a day, but she feels that her mental capacity does not offer any value in the labour market; Possibly because she hasn't been in the job market for years or because she is extremely tired as a result of caring duties.

The previous distance between Eugenia and her daughter has narrowed with the rise of the complicity between the two; the rapprochement has allowed them to recreate their relationship. Their relationship is closer to one of friendship, in which she, the mother, talks to her daughter about her negative feelings and then she feels relieved.

Eugenia had a difficult childhood. Her parents were both alcoholics and very rude with her and her sister. She is aware of the difficult life her mother had in the past and would like to make her final years more pleasant.

She is mad at her sister for not participating in the elderly care arrangement. Eugenia thinks her sister does not understand what care involves on a day-to-day basis. She knows that her mother was rude at her sister, as her mother was rude to her, but Eugenia has been able to go over and wish for a better life for her mother.

Eugenia is facing problems in her marriage. Her husband has his own life and is not concerned about Eugenia's emotional situation. He goes to work every day, he comes back and while they eat dinner together, they never talk unless something urgent comes up. Eugenia is not sure if their relationship's deterioration has to do with her role as her mother's carer; she notes that they have had marital problems have since they have been together. She recognises that due to the emotional and physical tiredness of her caregiving role she hasn't put any energy on fixing her marriage. Her main priority is her mother's care.

Two interviews were conducted to Eugenia, both lasted more than an hour and were held at her place. Only her elderly mother was present, lying in her bed at her bedroom. Eugenia was constantly checking on her during the interviews.

18. Fátima

Fátima is 46 years old. She comes from a middle-income household. She is the main carer of her 85-year-old moderately dependent mother. Fátima lives with her mother, her three children and her husband. She is the youngest of a phratry of five. None of her sibling participate in the elderly women's care as much as Fátima would like, so she is angry with all of them, specially with her sisters. Fátima would like to have a job and take vacations with her husband and children, but she cannot as she is responsible for her elderly mother's care. Fátima finds her situation unfair but she has no support, she has no choice.

Fátima experienced the gradual nature of cohabitation. She married 18 years ago and moved out of Santiago to live in the north. When she had children, her mother usually travelled to her daughters' house to visit her and help her caring the children. When Fátima moved back to Santiago, her mother was used to staying with her, so Fátima's mother would spend a night or two at Fátima's place was maintained even though the mother had her own house in Santiago. As years passed and Fátima's mother's began needing help, she stayed more often in Fátima's place, until one day, they decided that she should live definitely with them. Fátima's mother agreed.

Fátima is in charge of everything that has to do with her mother's care. She has set five daily alarms on her mobile phone to remind her that her mother needs to take a medicine. If ever she needs to leave house, she makes sure that it's either not at a time that her mother needs to take a medicine, or that there will be someone to give the medicine to her mother in her place. Every day, she wakes up at 6h to prepare breakfast and arrange her kids to go to school. After a normal day she is always very tired, but even more so the mornings she has to go to the primary health centre to set up an appointment with her mother's doctor or when she has to take her mother to the primary health centre.

Fátima rarely stops caregiving. When her children are at school she cares for her mother, as she is in charge of all caregiving duties. When her children are back from school combines the attention between her mother and her children. In her words, "I never end." She also referred to the fact that as her children are older, she is almost done with their caring responsibilities, but as her mother ages, she requires more intensive care. Fátima postponed her professional career while raising and caring for her children; although she would like to look for a job, being her mother's carer hinders her desire to seek employment.

Her husband works as a school principal. Fátima's mother receives a monthly basic solidarity pension (around 130 euros) and is enrolled in the public health system. As a middle-income household, neither Fátima, her mother nor the household receive anything else in terms of public support. Fátima has been out of the labour force since her children were born. In the case she wanted to have a paid job, having been out of work for so long would only make her eligible for jobs that do not pay a good enough salary to pay for an external carer. Fátima is stuck in the middle: she doesn't have the means to externalise care and she is not eligible for public help. She thinks it's unfair and strains her.

Fátima is the youngest of five siblings. She has three sisters and a brother. She lives in constant indignation because she finds it unfair that none of her sisters take on the role of carer of their mother in an active or regular way. She would like to take turns with her sisters to care for her mother. She would like to be able to take vacations with her husband and children while one of her sisters cares for the elderly mother or even have a part-time job as her sisters do. Fátima does not accept that they don't take on the role of carers. They are all women, she says, they all have a nuclear family and they all, as human beings, need to do things in life other than elderly care. Fátima's does not mention her brother, her anger is directed towards her sisters, not her brother.

For her, the fact that her sisters are all working and do not have time is not a valid excuse for not participating in the care arrangement. Fátima would like to have a job as well, but her role as main carer eliminates that possibility. The contrast between her situation and her sisters' and the perceived illegitimacy of their excuse for not participating makes her upset and angry with her sisters. She experiences her daily life as carer with pressure as a result.

For Fátima, the most difficult part of her situation is dealing with the fact that her siblings do not take part of the care arrangement. She is constantly angry towards them, a feeling that also affects the relationship with her mother and with her own nuclear family. Her historical cohabitation and the historically good relationship she has had with her mother are the reasons why she ended up taking the role as her elderly mother primary caregiver. The role now puts pressure on Fátima's life because the conflict arising from the fact that her siblings do not help with the elderly care as Fátima expects.

Fátima has always been close to her mother. Fátima's mother is the person Fátima sees the most, practically the only person she sees on any given day. The everyday routine of her mother's care without the support of her siblings makes Fátima more irritable towards her mother and their past good relationship has changed. Fátima regrets the change in their relationship, but she finds it difficult to revert it, she is tired and any effort is difficult for her.

Fátima has a very supportive nuclear family and a positive relationship with her husband. With her eldest 17-years-old daughter she has a special relationship; her daughter sympathises with her in her indignation with the rest of her family, and she lives her mother's feelings as if they were her own.

The ideal care for her elderly mother would be to count on her siblings' support. She would like to continue living with her mother and being her main carer but with the active participation of all the phratry. Fátima experiences the moral obligation to care with pressure as it hinders her possibility to invest in her own projects. If her siblings were equally involved in her mother's care she would be able to develop other aspects of her life. Two interviews were held, both at Fátima's place. Both lasted one our and a half. The elderly was inside her bedroom during our interview and I did not meet her. Fátima was very open to talk about her caring experience and showed very vivid emotions while she talked, especially when expressing feelings towards her siblings.

19. Florencia

Florencia is 45 years old. She is the main carer of her elderly mother with Alzheimer's. She is single and has no children. Her elderly mother lives with her. Florencia is single and her mother a widow; Florencia's father died eight years ago, which coincides with her mother's health deterioration. Both Florencia's father and mother worked when she grew up. Both her mother and her father worked at a school, she worked the school kitchen, he was the guardian. Florencia attended the same school. Florencia has never left the parental house.

Florencia's mother first lived in a nursing home when she was first diagnosed with Alzheimer's disease. The cost of the nursing home, in addition to the medicines and Florencia's transportation costs to visiting her mother added up to more than Florencia's salary. Florencia decided to take her out because she did not receive adequate care. Her mother lost weight and had recurrent falls. In addition, Florencia was spending almost all her salary on the institution, so preferred to quit her job and have her mother at home under her full time care. Florencia's household income was reduced to her mother's pension and her dead father's alimony (a monthly household income of approximately 360 euros). This new pension-based income was more or less equal to what she received after discounting for the costs of the nursing home.

Two years after quitting her job and remaining out of the labour force, she has returned to work as a digitizer, working for the same company that employed her before she assumed full time caring responsibilities. They offered her the possibility of working from home with the ability to choose her working hours. Florencia can now have a salary and a continuous work experience while caring for her mother. Although it is not an onerous salary, it is better than nothing. Importantly, her digitizer work allows her to disconnect herself from her caring duties, offering a respite from caregiving.

Florencia feels her mother is her child. This is evidenced in her home's decor. Her elderly mother spends her day in the living room, which is decorated with toys and stuffed animals that Florencia has bought for her mother. Florencia and her mother have always lived together and have had a good relationship in the past. Today, Florencia does not recognise her mother in the elderly woman she cares for. Alzheimer's disease has changed her personality and makes her very dependent on Florencia.

The most difficult part of Florencia's daily life is her loneliness. It is difficult for Florencia to maintain social relations outside the care relation; she centres her social life in her relationship with the elderly due to the extensive number of hours care entails. Florencia is happy to be her mother's carer despite her situation of isolation because she has been able to maintain the good relationship with her mother. The good relationship is due to the fact that Florencia sees her mother as her child. Role reversal explains the sense of fulfilment in Florencia.

Florencia is grateful from what she received from her parents during her life. Sometimes she wishes she could find a partner, but she knows that at this time of her life, caring for her elderly mother, it would be difficult. Her present and future loneliness anguishes her.

One interview was conducted in her tiny apartment. Her mother was in the same room, but in her own world due to her cognitive deterioration.

20. Francisca

Francisca is 42 years old, married and has a two year old daughter. She is the main carer of her moderately dependent 88-year-old mother. Francisca lives with her husband and daughter. Her elderly mother lives in her own apartment. Due to a recent hospitalisation and deteriorating health condition, the elderly has stayed in Francisca's apartment a couple of days a month. Francisca prefers that her mother stays with her given her frailty, but it is not easy to convince the elderly to leave her own place.

Francisca has a brother who does not participate in the care arrangement. Francisca is mad at him. She says it's not fair, he says he doesn't have time. Francisca is seven years younger than his brother and she used to care for her brother's children whenever he left his children in her mother's place, where Francisca lived until she got married four years ago. Francisca complains because she had to postpone any plan she may have had to care for her brother's children. She remembers this as especially difficult time because at the time she was in university studying engineering. She needed to study but it was difficult with the children around. Despite the difficulties, she never hesitated in caring for her brother's children. Now she expects her brother to give back. She would like her brother to remember this and take action regarding their mother's care. Francisca still doesn't find the courage to talk to him about it, however. Their relationship has changed and has distanced, but they still see each other once in a while.

Francisca works full time as an environmental engineer in the same company as her husband. Two months before our interview, Francisca was absent from work while her mother was hospitalised for four weeks. Francisca discussed an informal arrangement with her employer that allowed her to be absent for the entire month and keep her job. She took all of her and all of her husband's vacation days, which totalled one month. She recognizes she has an understanding supervisor, and is unsure she would have been able to be with her mother if she was working for a different employer. If that were the case, she would have had quit her job in order to be able to care for her mother.

She has always been close to her mother. They have always lived together. Her mother was a single mother and raised her children by herself. She was a cleaning lady and she was able to pay University for her children with a big effort. Francisca and her brother are the first generation in their family that attended University. Francisca is aware of all the sacrifice her mother did along her life for her children and is very grateful for that. Her husband and her daughter are very close to the elderly and they love having her at their place. Neither her husband nor her daughter has ever said anything to Francisca because of her commitment to her mother's care.

The interview was conducted at Francisca’s workplace in the evening. The workplace has a nice garden where we had our conversation. It lasted one hour.

21. Isabel

Isabel is a 51 years old. She comes from a low middle-income household. She is the main carer of both her dependent parents. Her father has severe dependency; her mother has low dependency. Isabel is the sixth of nine siblings. She lives in her own place; one of her brothers, a plumber, lives with their parents. Isabel is the main caregiver even though she does not live with her parents and her brother does. She lives 20 minutes away from her parents and goes on a daily basis. Isabel used to work as a nanny. Her husband died around the same time her parents started needing more help with daily life tasks. She began receiving her husband's alimony and decided to quit her job and dedicate to her parents care. She lives off the alimony she now receives.

Isabel widowed five years ago and found a supportive partner eight months ago. She sees the big difference of a supportive partner compared to being alone. She does not live with her partner, but they see each other often. His company is the best respite from her caregiving duties.

Isabel arrives every morning to her parents' house and stays there until they have dinner every night. The brother that lives with the elderly couple cleans the house; he doesn't carry out any intimate care tasks.

Isabel was the one woman in the family available to become the main carer of her parents. One of her sisters has cancer and the rest are all in the labour market, her brothers were not mentioned as a possibility of caregivers. Two of her sisters visit the elderly couple often and help Isabel with any tasks that need to be done while they are visiting.

Magdalene wouldn't take a paid job even if it allowed her to pay someone else to help her with care duties. For her, being the main carer is an answer to her conscience that tells her that caring is what she must do. She is out of the labour force as a result of her motivation to provide care.

Isabel lives with her daughter and her granddaughter. Before she became her parents' main carer she often helped her daughter with the child care. However, when she took on the role of the elderly care she stopped helping her daughter. This has caused her trouble in their relationship because Isabel's daughter doesn't understand her mother's position. She wants Isabel to help with her childcare, but Isabel won't budge even if her daughter is very angry at her. According to Isabel, she has already raised and cared for her daughter, her daughter should not continue to depend on her mother. Isabel thinks her role now is to be her parents' caregiver and when she has free time she prefers to spend it on leisure activities with her partner. She does not regret this attitude. On the contrary, she assumes her role as what should and needs to be done, no matter what her daughter thinks and feels.

Isabel's parents are beneficiaries of the Home Care programme offered by the municipality where they live. She appreciates the weekly visits and the respite she gets from those visits and she considers that the time provided is enough. More frequent or longer visits would imply a feeling of invasion by the part of a person external to the household, of giving something personal away to someone who is not trusted enough. Isabel mentioned that the limits to more respite lie in elderlies' willingness to interact with different people. Isabel says it's her mother who doesn't like having strangers at home.

Apart from her partner, Isabel finds strong support in her faith in God. She recognises that she cries very often because she is tired and because she suffers seeing her parents in their current state. When she feels sad, she prays to God to give her strength to continue with her role and give her company to live her role in the best possible way.

One interview was conducted with her. It was done at her parents' place, in a small living room. Her mother and her father were both in bed, her father because he is severely dependent and her mother because she was not feeling well that day. Isabel's brother came to say hi and then he left the house.

22. Josefina

Josefina is 64 years old. She belongs to a wealthy family. She is the main carer for both her father (94 years old) and mother (91). Both elderlies have moderate to severe physical and psychological dependence. They have needed 24-hour care for the past five years. Nurses provide direct care for her parents, who still live in their own home. A maid also assists in household chores and some care tasks. Josefina's parents have enough savings to allow them to afford this arrangement. The remaining caring tasks are covered among the four siblings, coordinated by Josefina.

The five years Josefina has been providing care have been long and heavy for her. She finds that organising and managing external care, and organising and managing her parent's household are particularly difficult. Part of the difficulty Josefina experiences has to do with seeing her elderly parents deteriorate (especially hard for her is to see how her mother, who has an advanced Alzheimer's, mistreat her father after having been a good couple).

For Josefina, ideal care is in a nursing home. She has been able to compare her parents' arrangement with that of her mother-in-law's, who spent her last years in a nursing home. Josefina notes that the difference for the elderlies is important, as is the difference for the main family carer. Josefina would like to spend her last years in a nursing home, and she has been explicit about it with her daughter.

Josefina is retired and has raised all her children. She is happy in this regard, to be able to dedicate herself fully to her elderly parent's care. Josefina has three sons, a daughter and six grandchildren. Because she cares for her dependent parents, she doesn't see her children or grandchildren very often. Her daughter is not happy with the fact that her mother is not available to help her with childcare. Josefina doesn't want to change the situation for the time being.

Josefina is the main carer because she wants to return the support they offered in the past. Josefina says her parents were exceptional parents and describes in details all their virtues. She carers for them because they deserve it, they were too good as parents in the past. This motivation for reciprocity is felt as a binding obligation. She doe not question her role as carer.

Josefina is clear in recognising that the good relationship she has with her siblings is sustained, to a large extent, on the fact that parents' pensions and savings were high enough to cover care costs and that all members of the phratry have a good financial situation.

Josefina brings up the difference in the relationship with daughters as compared to sons. She has three sons, a daughter and six grandchildren. The relationship with her daughter is more delicate than that with her sons. It's not always neutral and there are conflicts once in a while because she is not visiting her granddaughters or she is not available to spend time with her daughter. Josefina's biggest respite is going to her beach house with her husband, ideally every possible weekend, if one of her siblings assumes the elderly parent's care for the week-end. The fact that she is not available either on weekdays or weekends is not welcome by her daughter.

The interview with Josefina was conducted in a fancy café in a Santiago. We were in the terrace. She was nice and willing to tell me all about her parents and her story. The interview lasted for two hours. While we were having the conversation, two nurses were walking in the sidewalk of the street in where we were having our interview. The nurses were carrying two elderly persons in a wheelchair. They were Josefina's parents.

23. Lucía

Lucía is 56 years old; she comes from a low-middle income household. She is the main carer of her elderly father. She is a single mother of three children. She lives with her 10-year-old daughter and her elderly father. None of her eight siblings cooperate with the elderly care in any possible way.

She lives with financial constraints. Her father's pension is spent in covering one of his grandchildren's tuition (one of Lucía's brother's was sued by his ex-wife because he abandoned their children; since the man does not have the money to for the tuition of his children, it is the grandfather—Lucía's dad—who must, by law, pay for it). Lucía has to work – and does work – to keep the household running and her father and children fed.

Lucía works because she needs to maintain her household, because she needs the money. She works as a cleaning lady for different families every day until 14h. She also irons and washes neighbours' clothes so she can earn extra money while working at home and remain attentive to her father needs Lucía has reduced her working hours as a full-time informal cleaning lady to make time for her care work. She is all alone caring for her elderly father and her 10-year-old daughter.

Lucía gets mad at her siblings because she cannot explain their lack of interest and involvement in the elderly care, even after considering that he was a good father and that he is now a vulnerable person in need of others to survive.

The ideal situation, for Lucía, would be to receive a monetary compensation from the government for her care work. With the monetary compensation she would not suffer the economic constraints she faces every month. She would prefer to receive money so she can stay at home with her father rather than to receive respite or the possibility to combine in a balance way a paid job with her care work. During the interview, Lucía mentioned that if she ever met her municipality's mayor she would ask him to give a salary to carers of elderly parents so that they could stay at home rendering a good quality care.

Though currently alone in providing care, she doesn't want to ask her own children for support. She thinks it's not fair since it's not their role or obligation but hers. Lucía also suffers diabetes and a vision problem. She is now afraid that something could happen to her before her father dies and that she will have no option but to ask her children for help.

Lucía is sometimes mean to her father. They started cohabiting a year ago. Prior to that, her elderly father lived in the countryside alone; his wife passed away five years ago. Lucía and her father's relationship has been in adaptation since they began cohabitation. According to Lucía, her father was used to be attended by his wife. When he widowed he established a routine and schedule that is incompatible with Lucía and her daughter's habits. For example, her father likes to watch television with a loud volume late into the night. Lucía gets mad with this habit because he is not deaf and his room is right next to Lucía's daughter's room who wakes up early to go to school. He was also used to permanent service by his wife and expects Lucía to do the same. Although Lucía is very engaged in her father's care she refuses to do some tasks, like ironing all his clothes, as her mother used to do. She admits that their relationship has changed and that, little by little, they are getting used to the care situation.

Whenever Lucía needs respite, she goes to her well-equipped kitchen and bakes. Her house has the sweet scent of a recently baked pastry. She sells what she bakes in her neighbourhood or at her daughter's school. Her face illuminates when she refers to her cooking passion.

The interview was conducted in her living room. Her father was in his room in the second floor. Her daughter was at a friend's house.

24. Lucy

Lucy, a 45 year-old middle-low-income woman, is the mother of a 19-year-old son and gives care for her moderate and severely dependent parents. Her father has Alzheimer's disease and her mother has a physical dependency, she can't walk.

Lucy and her son have always lived in Lucy's parent's house. They are originally from a city in the north of Chile, Antofagasta. They migrated to Santiago 20 years ago looking for a better life and job opportunities.

Lucy describes her family model as a matriarchy. Today, that model is only symbolic, because Lucy is completely in charge of all house matters. Her mother, however, still wants to control everything and Lucy senses that pressure. The elderly woman used to use a room on the second floor, but decided to sleep in the living room of the house, in the first floor, because she did not want to be isolated and wanted to be aware of everything that goes on in the house. Lucy's mother spends her days and nights in the same couch. Lucy feels as if she is controlled by her mother the whole day.

Most part of the caring responsibilities lie on Lucy. Her 19 year old son participates in carrying out some caring tasks, but has never been involved with his grandparents' intimate care. Lucy's only sister does not participate in the care arrangement in any way, shape or form. Although she faces many daily constraints in being both her mother's and father's main and only caregiver, she wouldn't feel comfortable if her sister was responsible for her parent's caring. Lucy thinks her sister has no competencies in care and that she is the best suited for it.

Lucy's parents participate in the Home Care programme offered by the municipality where they live. Lucy enjoys the weekly visits of the external carer and uses that time to carry out home tasks without the pressure of surveilling her parents at the same time. Whenever Lucy needs respite, she does home tasks. It's her only disconnection of her care role, although she needs to be there and aware at all times if something happens to them.

Two years ago, Lucy desperately needed a salary to pay for her parents' health and social care costs, and to maintain her house. Because of the difficulty of finding a job in Santiago she took the decision to leave town to work as a music schoolteacher in Antofagasta. Lucy was born in Antofagasta and a relative connected her to this opportunity. Antofagasta is 1,380 kilometres north of Santiago, and traveling from one city to the other is expensive. Her son, who studied, cared for Lucy's parents and did the housework with some help from Lucy's sister.

Four months later, Lucy had to quit her job in Antofagasta because her son was unable to provide care to his grandparents, do the housework and study at the same time. In addition, Lucy's sister did not fulfil the promise to help out. Lucy came back to Santiago and after desperately looking for a new job, she finally found one at a school close to her house. Usually while teaching, her father with Alzheimer's disease would visit her to tell her that her mother needed urgent help. It was generally not the case, and she was constantly and needlessly interrupted. While at work she was worried something could happen to her family. Lucy was laid off two months ago. She is convinced that she was let go because the school administrators were tired of her father's interruptions. She is desperately looking for another job. This job has to be close to her house because she needs to go to see her parents during lunchtime, to give them lunch, their medicines and make sure they are fine. So far, she hasn't been successful. Although Lucy loves being a music teacher, combining the two roles was very challenging because of how care and what care means for her interfered with her job. This would allow her to have paid work and provide care and prevent financial constraints.

Lucy doesn't have an active social life. She would like to have time to maintain contact with her school. Whenever she has free time, she prefers to rest at home.

Lucy feels grateful by the support she receives from her son once in a while, even though his involvement in care consists in sporadic support with tasks that require physical force or surveillance of the elderlies while she has to go out of the house for a while.

This interview was conducted in Lucy's house. Both her parents were present during the interview. Her father, with a cognitive dependency, did not participate in the conversation. Lucy's mother was present and wanted to participate in the interview. However, although she was there, Lucy softened her voice to speak about issues that she didn't want her mother to hear.

25. María

María is 50 years old and the main carer of her 98-year-old mother. She comes from a middle-income household. She became her mother's main carer three months ago. The elderly has a moderate dependency, and spends a couple of hours a day sleeping in the living room or sitting quietly in the garden just looking at people passing in the street. María thinks her mother has depression, but they haven't seen a doctor to confirm this diagnosis. María has eight siblings (five sisters and three brothers). Of all her siblings, one was involved in their mother's care for a couple of weeks in the past; another sibling helps in the present. Her eldest sister cared for her mother for a few weeks when, as the result of an accident, their mother had to go to the primary health care centre on a daily basis. It was more convenient for her eldest sister to take responsibility, as the primary health centre is just in front of her place (María has to take two buses to get to the primary centre). For three months now, the elderly mother now lives with María.

For María's own family the cohabitation with the elderly is complicated in terms of physical space. In the house, they are now five: María, her husband, her daughter, her son and now her mother. They live in a small house and as there is no space in the house, María's mother sleeps in the living-room couch (not a sofa bed, just a sofa). María's children complain they are not allowed to make noise or watch television in the living room after 22h once their grandmother is sleeping. María prefers the physical space constraints to the time and monetary costs of commuting to her mother's house. She is not worried about her son or her daughter's complaints. For her, as they do not help out with the elderly care, they don't have the right to complain. Despite the dissatisfaction with the space constraints they have a fairly good relationship and furthermore, caring for the elderly has strengthened the relationship with her teenage daughter as they have started having more conversations and quality time together. María's husband is nice and supportive to her, whenever she loses her patience with her mother, it's her husband who calms her down.

María assumes her role with resignation and it does not pose major problems to her. She is affectively detached from her mother, she recognises that she was not a very nice mother so it is kind of difficult to be nice to her. She says she loves her but with a sort of distance. She thinks that her other siblings do not visit her often because of how she was in the past with them, a cold and distant mother. However, María does not complain about her role, and if she could pay someone to help her with care duties she wouldn't do it, she prefers to be her own mother's caregiver. She is not in the labour market and spends her days around her mother's care. She likes to run every morning before her husband goes to work, she thinks that exercising keeps her positive and energized.

The interview with María was conducted at her house. She lives in a modest neighbourhood. She does not participate in any elderly social care program offered by the municipality because she is not aware of the offer, eventhough she lives in a municipality that offers many of SENAMA’s programmes.

26. Marita

Marita is 79 years old and lives with her severely dependent 103-year-old mother. She comes from a high-income household. She delegates some caring activities on a Peruvian migrant external paid caregiver. Marita's mother had a heart attack, which led her to a three-week hospitalisation eight years ago. Upon discharge, her two daughters and two sons decided that she could no longer live alone and she went to live with a son and a daughter-in-law before living with Marita, her eldest daughter. They decided to take the elderly woman to Marita's house because it was, according to them, more logical that the elderly lives with a daughter than with a daughter-in-law and a son. After only a couple of months, the elderly woman came to live with Marita and her husband.

Not long ago, Marita's 103-year-old mother stopped receiving her pension. Fortunately, Marita's five siblings have a good financial situation and collectively afford their elderly mother's care costs. They also have a good relationship so it has never been a problem to agree with money issues related to their mother's care.

Marita has hired external carers for their mother care for the eight years. At the beginning, they hired formally educated and certified nurses from a specialised company. But some time after, Marita found the extra expense for a nurse was not necessary because they were paying for technical knowledge that was not necessary; at that time her mother didn't require complex care. Also, the dispatched nurse changed almost every day. A system with such rotation did not offer any emotional support and made it seem like carers were strangers in her house. Marita did not feel her mother was completely safe in the house alone with a different nurse every other day.

In order to find a more stable and closer service, Marita and her siblings decided to hire an older woman that provided domestic service in the past to one of the sisters. This woman already knew their mother. The new full time carer was originally from Peru, as have all those Marita has hired since then. Marita is satisfied with the work these women have done and prefers them to professional nurses.

For Marita, one of the most difficult parts of being her mother's main carer is what she calls the 'externalisation issue', the fact that she cannot trust external caregivers immediately. When speaking of difficulties, Marita also refers to the worry she feels every time a hired carer announces she is leaving, something that has happened often with the Peruvian women they have hired. Fortunately for her, Peruvian immigrant carers are a tight network and recommend each other if they have to leave.

Marita has a daughter. Her daughter lives in the countryside since she married 25 years ago. Marita received her grandchildren at her place while they attended University in Santiago. They are all graduated now and Marita feels relief. Now she is happy to have time to be dedicated to her mother's needs.

Marita has a nice and supportive husband, but he is not involved at all in elderly care. He spends most of his time at work. He leaves every morning at 7h30 and comes back tired at 20h every night. Marita's husband is 84 years old. Before they started living with her elderly mother, her husband was very supportive with the idea of living with the elderly. He promised his wife he would stop working so they could spend more time together. However, he changed his mind and still works.

Marita and her mother have always had a positive relationship. For her, elderly care is not experienced with a high level of pressure, but, when thinking about the most appropriate care, she says that ideal care is care by professionals in a nursing house, and not care provided by nurses or other external caregives in a daughter's house.

The interview with Marita was conducted in her apartment in an expensive Santiago neighborhood. She was reserved and nice; as the conversation flowed she became more open to sharing her emotions and daily experience as her mother's main carer. The elderly mother was at her room, I visited her at the end of the interview. A women sat by the elderly at her side. She was the external caregiver from Peru, she shares the room with the elderly, her bed was next to the elderly's bed.

27. Mauricio

Mauricio is 54 years old, and. He comes from a low-income household. His house is small and tidy. He is the main carer of both his mother and sister, they all live together. Mauricio's mother is dependent, his sister has a low physical dependency. He is the only man in his nuclear family. The three have always lived together. His mother used to care for his sister until she also started needing help. Mauricio, who has always lived with his sister and mother took on caring for his mother and sister when his elderly mother was no longer able to provide care and actually needed it. He does all the caring tasks but he does not provide intimate care to any of the women. Female neighbours take turns to provide intimate care to them.

For several years since the 2010 earthquake in, Mauricio shared the bedroom with both his mother and sister; the two women slept together in a single-size bed. The old lady became scared after the earthquake and she could not stand sleeping alone any more. Mauricio preferred to be as close to her as possible during the nights in case another earthquake hits. Recently, though, Mauricio moved to his own bedroom.

Caring for the two women care occupies Mauricio's entire; it is no possible for him to combine care with a formal job. He provides care by himself, he cannot afford external care. The family lives off her mother and her sister's pensions. The financial constraint is the most difficult part of Mauricio's situation and is the main cause of most of the difficulties he faces. The lack of earnings does not allow him to visit a dentist to fix his falling teeth (dental health care is not part of the public health system in Chile and is very expensive for the majority of the population).

Mauricio stopped working to be fully dedicated to his mother's and sister's care. As he is out of the labour market, he is not saving for a retirement pension. No one else in his social network was available to take the responsibility of his mother and sister's care. For Mauricio, the ideal care would be one that is visible by the government and is compensated in some way.

His neighbours help, they are an important source of support. They are, in fact, the only source of social support he receives, with the exception of a cousin who visits him and his family once in a while. Mauricio explains the support from his neighbours because they, in the past, were good neighbours, especially when his mother was autonomous and he had more time to spend with them. Mauricio frames his neighbours' support in terms of reciprocity. He is scared that one day they will stop supporting him one day if get tired of giving, especially now that he and his family cannot give back as much as they receive.

He has never questioned his role as carer; he says he will never give up his role because his mother has had a very difficult life and he would like to repair it in her last days. He would like to give his mother a pleasant end to her life. Though in Mauricio's case no one else was available to take on the role as carer, he does not mention the unavailability of others as a reason to provide care; he still finds it a personal option to give his mother a good end-to-life. Repair his mother's life gives Mauricio a sense of accomplishment; he would never put her mother in a nursing home even though it would allow him to find paid employment and reduce his financial constraint. A driver in this sense for reparation is the fact that Mauricio perceives his life before care as a very satisfying one (he had paid employment and was financially independent, he partied and travelled around the country, for example).

Mauricio has always had a good relationship with his mother and his sister. The positive relationship persists today. However, there are some moments in which Mauricio would like to be alone and take a rest from his caring tasks. In those occasions he closes the door of his bedroom (now he sleeps in a different bedroom than her sister and mother) and watches television. He watches TV in his room when his neighbours are visiting his mother and sister.

The interview was held in the Mauricio's house's dining and living room. We then visited his mother and sister who were in their bedroom.

28. Ofelia

Ofelia comes from a middle-income household. Ofelia is the main caregiver f her 89-year-old father. Her father lives next door to her and has a moderate dependency. Ofelia lives with her husband and her youngest daughter. Ofelia works full time as a teacher in a school for deaf children. She has worked for 37 years as a teacher in the same school. Ofelia adopted the role as her father's main carer when her mother died,

Ofelia comes home from work every day in the afternoons and goes directly to her father's place to see how he is doing. She then carries out the household chores in his father's house, heats and gives him dinner and his medicines. Then she goes back to her place, she does all her household's chores, prepares dinner for her family and then has dinner with her husband and daughter. When they go to bed she continues working to prepare his father's food for the following day. She is the first one in her family to wake up, takes a shower and goes to her father's place to give him his medicines and breakfast. Although she carries out multiple roles, Ofelia says she would never ask her daughter for support, even though she is tired and could use some help. Her daughter's priority is her studies.

Ofelia recognizes she is tired. She said she would like to stop working because she is tired of her double shifts, one at the school and one at home. But she has to keep working because she needs the money and if she quit her pension would be very low. She receives no help from any of her relatives or from her husband when it comes to her father's care or household chores.

Her father used to receive a pension from the private individual-savings accounts system but his private savings have run out so he only receives a basic solidity pension from the government.

Ofelia is upset about her situation. She doesn't like leaving her father alone while she is at work, because his frailty is increasing and he has started to lose his memory. She would like to stop working and stay at home with her father, or would like to be able to pay someone to help her with her father's care while she is at work. But she faces a difficulty: if she stops working her pension wouldn't be enough to maintain her living standards (although they are not high) nor her salary is enough to pay an external carer.

The most difficult and painful aspect of Ofelia's life is the relationship with her husband. Ofelia has become sorely distanced with her husband. She became her father's main carer because she was the one in the phratry that lived close to him and does not receive any support from her siblings. She would like things to be different, she would like to be less involved in her father's care but since no one else from the phratry gives support she feels she has no option. She does not find a solution and feels the pressure of elderly care and its consequences for her spousal relationship.

Ofelia has the best recollection of their past family relationship and the good time they used to spend together, especially during the summer holidays when they travelled, camping, throughout the country. All of it is gone: no more vacations, no more leisure and quality time together. Ofelia's involvement in her father's care, added to her teaching job and household tasks have left her without time to spend with her husband. She regrets and suffers, she would like to be closer to her husband as they used to be, but the sum of her daily life responsibilities limits her.

The interview took place at Ofelia's father's house, in the evening. Her elderly father came in and out of the living room where we were having our conversation. The elderly man told his daughter about a woman that rang the bell during the day and tried to get into the house saying she was a cleaning lady. The elderly man allowed her to enter the house (although it was not true she was a cleaning lady and they were not expecting her), she spent a couple of minutes and then left. Ofelia became mad at her father for letting this woman in. She is confused and doesn't know how she is going to manage this situations having at the same time a paid employment. Ofelia looked tired and socially isolated.

29. Paz

Paz is 54 years old. She comes from a low-income household and is the main carer of both her parent-in-laws. The elderly she cares for are 80 and 87 years old; both have a moderate dependency and live with her. Alejandro, her husband and the elderlies' son, cleans the house and prepares food for his parents. Paz brought the elderly couple to live with her four years ago, when she realised that their health had deteriorated and that they could no longer live alone. Back then, the elderly couple lived with one of their daughters, one of Alejandro's sisters.

Paz has an informal paid employment outside her caring work responsibilities. She usually works weekend nights with her partner, Alejandro, as mariachis (street singers). She has been singing for 30 years and loves her job. She also does it because her household needs the money. Although they would prefer not to leave the elderlies alone while they work, it's not a big source of worry because Paz and her husband enjoy singing and forget everything else while they sing.

Paz or Alejandro do not receive any support from friends or relatives. The elderly couple are beneficiaries of the Home Care programme in their community. Paz is happy with the weekly 2-hour visit of the Home Care external carer and considers that the time provided is enough. More frequent or longer visits would imply her feeling invaded by a stranger. If the visits were longer, Paz would feel something personal and intimate being given away to someone who is not trusted. Paz also mentions that the elderlies are not willing to interact with other people, also limiting her interest form more respite. She says the elderlies get tired because they are not used to interacting with 'people from outside'.

Paz feels tired and lonely in her daily life as carer of her parents-in-law. She says God gives her strength and force. Her house is full of religious images and candles, with flowers around these images. Paz finds strong support in her faith and there lies the motivation to remain as the main carer of the elderlies, despite the difficulties she faces. She says she loves the elderly couple and will care for them until their last day. She feels it's God's mission for her.

Alejandro, her husband, has siblings. The lack of support from his partner's phratry negatively affects their relationship with them. This relationship also affects their care experience. The relationship with the extended family is the most difficult issue she faces as a main carer. Paz cried during the interview when speaking about this relationship and the associated feelings.

Money was an important issue in the conflicts with the extended family. Paz and Alejandro do not receive any monetary support from the rest of the family although they face important economic constraints. In 2015, they receive a little more than 120 euros (85,000 pesos; the pension was then increased in 2016 to 95,543 pesos or 135 euros) for each of the elderlies, as a result of the Chilean national solidarity pension. Yet, as Paz puts it: "What can one do with the

85.000 pesos per month [120 euros]?". Paz's siblings-in-law say she and her partner want to keep the elderly just to receive their pensions, something Paz finds ridiculous because the pension cannot even cover for the medication they need.

Paz has two children. She has a positive relationship with both of them. She is especially close to her daughter, who is experiencing a difficult moment in her life because of domestic abuse. Paz is very touched by this subject, as she, herself, was also a victim of domestic violence with her previous partner, the father of her two children. Her role as the main carer of the elderly couple is not an impediment to spend time with her daughter and give her support. Her daughter visits Paz often; Paz visits her daughter every other week while her partner, Alejandro, stays with the elderly couple.

We had two interviews, both at her place, in Paz's bedroom. The elderly couple and her partner were in the living room. Paz showed vivid emotions throughout both interviews.

30. Paula

Paula lives in a low-income neighbourhood in Santiago, in modest, cosy and well-equipped home, with flowers in the garden. She is 54 years old; she is the single mother of one twelve year-old boy. She is the main carer of her 92-year-old mother with a low dependency level. Paula's mother needs help with some instrumental life activities. Paula has four sisters and two brothers; they all have a very good relationship. Her sisters participate actively in their mother's care; her brothers provide financial support. Paula excuses her brothers and their lesser and passive involvement in the care arrangement by saying that they are men. The lesser participation of their brothers is not at all a cause for conflict.

They have always been a united family. Paula's parents were rural migrants and settled in Santiago sixty years ago. They settled in the city and raised their numerous family, not free of difficulties. They have lived in the same neighbourhood since their arrival. Paula and all her siblings - with the exception of one sister - still live in the same neighbourhood.

The elderly mother widowed twenty years ago, and moved to Paula's house five years ago. Cohabitation is not a source of constraint, the two women enjoy each other's company. Her mother's pension does not cover her basic needs.

Paula, with the help of her siblings, has been adapting the house to the elderly's dependency condition. They have built a new bathroom and moved the elderly's bedroom to the first floor of the house. These arrangements have been made with the financial help of all of Paula's siblings.

Paula has a part-time job as a saleswoman. Despite the lack of monetary resources to externalise care, Paula juggles complicated care arrangements to be able to work, even considering that the financial returns to her job as a part time saleswoman are limited. She likes her job and values the money she earns. She gives her mother breakfast every morning before going to work. Her sisters take turns to care for their mother while Paula is at work. Paula knows her mother is in good care when she is at work. She counts on her sisters for other forms of support as they help with household chores (e.g. cleaning her mother's bedroom and washing her clothes).

For Paula, being her mother's main carer and being employed does not impose pressure in her life. Paula is one of the few cases in the study that maintains a positive relationship with her siblings. Paula attributed this to the teachings and upbringing of her mother. She values the support offered by her sisters and her flexible working arrangement.

Two interviews were conducted to Paula, both in her house. For the first one, on a Saturday morning, her mother was around and participated in the conversation by telling the story of their settlement in Santiago. Little by little other family members arrived to Paula's house. They usually gather on weekends for breakfast. Another interview was conducted the following week, with only Paula and me at her place. Her mother and son were at one of Paula's sisters having a snack.

31. Penélope

Penélope is 50 years old. She comes from a high-income household. She is divorced and lives with her three daughters. The two eldest are studying at the university, the youngest, aged 16, is at the school. Penélope is the main carer of her elderly parents who live in Curicó, a town two and a half hours away from Santiago. Penélope's father has a low dependency level, and her mother a severe dependency due to a cognitive deterioration she developed after a cancer. The elderly couple live alone, and receive help from an external paid woman who comes daily to help them with daily home tasks. Whenever there is an emergency Penélope has to be there for her parents. She sets their medical appointments, buys their medicine and takes them to the hospital and medical exams; all in Santiago. She picks them up at the bus station and takes them to the doctor, she buys medicines and organises them to make sure her parents take them. Penélope calls herself her elderly parents 'health manager' of her elderly parents.

Penélope has one sister and two brothers. The three cooperate financially towards their parents care. Penélope, on the contrary, as she has a worse financial situation than her siblings do, cooperate with her time instead of money.

Penélope also works for pay, Mondays to Fridays from 9h to 18h as a school psychologist in a school attended by children from disadvantaged social backgrounds. She holds individual therapy sessions with students, meets with the school's teachers and meets with the student's parents. She recognizes she is often tired, but she is at the same time happy with the possibility of combining her parents' care with a paid activity. Helping vulnerable children and families in her job gives her a sense of fulfilment. She also appreciates the fact that she is able to manage her work schedule; she is able to decide when to have meetings with students and their families. She values the flexibility her job offers.

Penélope has a good relationship with her parents, particularly with her father. She still has issues from her past story that makes her relationship with her parents sometimes difficult. She says her mom was tougher than her father, she thinks it was because the sort of education her mother had. Her father was generous, patient and always made things flow well, without conflict. She appreciates from her parents the effort they made to give their children good educational and intellectual skills that allowed her to develop personally and professionally. However, she says that now that she is an adult she has serious problems handling conflicts, she has anger issues and doesn't know how to manage them. Managing her emotions complicates her the most She thinks this may be due to how protected she was as a child. For example, she did not wear earrings when she was born (all baby girls use earrings in Chile when they are born) because her parents thought that could hurt her; they did not teach her to ride a bike until she was twelve because she could fall; they would not let her run. She claims she was brought up as a good little girl with no tools to face conflict. Penélope remembers her father as very ‘machista’. For example, her brother as he was a man did not need to make his bed in the mornings. As she was the eldest, she had to do the household tasks with her mother. Her brother had other obligations like going to buy bread. While her brother had permission to go out and play in the street but the girls did not.

32. Pedro

Pedro is 58 years old. He works full time, five days a week as an office assistant. He lives with his elderly parents; his mother has severe dependency. A month prior to the interview, Pedro's mother had a stroke that left her on a wheelchair and implied a high loss of functional and cognitive ability. Pedro's mother is constantly asking his son for emotional support. She wants him to give her company and stay close to her. When Pedro arrives from work, at 19h every weekday, her mother looks at him, stretching her hands to ask him to take her hands between his.

While Pedro is at work, a paid carer looks after his parents. When he comes home after work, Pedro dedicates himself fully to his parents. He receives support from his wife and, to a lesser extent, from his daughter. His two sisters take turns during the weekends. This allows Pedro to rest, regain energy and start Mondays able to balance his paid work and parents' care with no strong experience of pressure.

Pedro, his wife and daughter have always lived with Pedro's parents. They share the property, but live in different dwellings: a 5-meter corridor separates Pedro's house from his parents'. When his mother had a stroke and lost most of her autonomy, Pedro became her main carer because of the physical proximity between him and his mother. Pedro and his two sisters decided to keep the elderly mother in her house.

With his salary, his wife's earnings as a cleaner, and the monetary help from his two sisters' families, he can pay an external carer to take care of his mother while he is at work, from 8h30 to 19h. He has never thought of quitting his job to care for his mother full time.

Pedro receives a strong support in his caregiver role, from his sisters, wife, from an external paid carer and from his employer, co-workers, neighbours and friends. Balancing care work with employment is experienced with less pressure for Pedro, compared to other female middle-class carers.

Pedro's wife supports him in many ways. She understands that Pedro is less present and less available to be with her, and that he is exhausted at nights. She also helps him by performing some of the direct caring tasks, like bathing Pedro's mother and preparing her food. Pedro's wife's attitude and involvement exceeds Pedro's expectations. 'She is a queen' he says, referring to the emotional support and direct care she provides for Pedro and his elderly mother.

He says his employer has been very supportive. He can take a day or a half-day off to take his mother to the doctor or to visit her at the hospital if that's the case. He feels his employer and colleagues are understanding of his situation as they show concern and are permissive and comprehensive with his absences. He recognises that they are supportive with him because he is a man. If one of his sisters were the main carer they wouldn't receive the same support from their employers.

Despite the social support Pedro receives, he struggles with his mother's care. The hardest for him is seeing her mother's health deteriorating and having lost the relationship they had before her stroke. Pedro is slowly accepting that his mother will never be the same.. Nevertheless, he finds it difficult not being able to hold a conversation with her mother as they could before. The inability to hold a conversation increases his feelings of loneliness and the sadness that result from seeing his elderly mother's health deteriorate. He also dislikes the new relation he has with his elderly mother and misses the mother he used to have. His mother is totally different from the one he knew; she developed dementia after her stroke. Pedro's mother had a pivotal role in the family. She was a strong woman with a high emotional intelligence. He is slowly becoming emotionally ready for the caregiving tasks that lie ahead.

Pedro also struggles because he has no longer has time for himself. He is aware that changing the current care arrangement will not reduce the intensity of his care experience. His care ideal is far from that of a nursing home. He has never even thought about it. He thinks that that's what children are here for, to care for their parents when they are old. Pedro does not root his rejection of a nursing home in monetary constraints, but in children's moral obligation to provide care to their elderly parents. Yet, he does not question whether he should have external help or not. He neither question combining work with caring for his elderly parent.

Pedro's situation has, by far, fewer constraints than those of many other carers in the study. He has a strong social support coming from his wife, daughter and his two sisters. He has a fairly good economic situation that allows him to pay an external carer whom he trusts. He has a job and a supportive boss and colleagues. However, he experiences his role with a strong feeling of pressure. This feeling of pressure cannot be attributed to his situation, but from the fact that their relationship has changed. He can no longer talk to his mother the way he used to. He can no longer count on her. The relationship they had is now a painful souvenir.

Two interviews were conducted to Pedro. Both in his workplace at lunch time. At the first interview he was reserved and very upset. During the second one we were able to get deeper onto the relationships and emotional aspects of his life; the first interview was more about the description of his situation as a caregiver.

33. Pilar

Pilar is 61 years old. She is the main carer of her father, who lives next to her house and has moderate dependency. She spends all day in her father's house caring for him and sleeps in his house every other night.

She refers to herself as the "official family carer". She has been the main caregiver of her mother before she died, and she supported her cousins' care when their father was dependent. The skills for caring she has acquired throughout these experiences has given her a special recognition among her relatives. Today, if a nephew or niece suffered an injury, needs an injection or someone has a wound to clean, they will call her. Pilar accepts she is more involved in her father's care than her sister is. Pilar also has a better relationship with him than her sister does, validating further the fact that she, and not her sister is the main carer. This imbalance in involvement in care work is not a matter of conflict in their relationship.

Pilar is also satisfied with her husband's attitude towards her role as her elderly father's main carer. He doesn't intervene too much. He has never complained, he has always been supportive and nice to her. Pilar thinks that the fact that he is still working is of great help, because he works long hours so gets to their house just to eat and sleep.

Pilar belongs to a closely knit family. Most of her cousins live and have always lived in the same street as her. Their presence and good relationship is an important source of support for Pilar. The day of the interview, that took place at her house, a group of relatives were having the afternoon tea together at her father's place, we could hear them laughing. Pilar is active in the neighbourhood's Catholic Church. When her sister stay with her father, she goes to church and gives the Eucharist to the sick and elderly people who cannot go to church.

Pilar was one of the few cases of the study that, although tired because of her caring tasks, appeared to be happy and in peace. Her life history and the emotional support she receives from her family helps her to live her role with very low pressure.

34. Rebeca

Rebeca is 61 years old. She lives in a comfortable house with a beautiful garden in a high-income neighbourhood of Santiago. She lives with her husband and her youngest son; her eldest daughter is studying a Masters degree in the United States. She is the main carer of her elderly mother, who does not live with Rebeca. Rebeca's mother has enough savings to pay for her care and life expenses; she receives direct care from professional nurses. Rebeca's mother's savings pay for two nurses (one for the day, another for the night), for a household maid who does the cooking and house cleaning, and for the household expenses. Rebeca manages the external caregivers and her mother's household issues. Management tasks are difficult for Rebeca. Rebeca administrates the money, buys the food and the medications, deals with the nurses and the maid and manages the elderly medical appointments.

Rebeca has 8 siblings and 5 sisters. Two of her sisters live in Santiago and support Rebeca with their mother's care. As Rebeca was always the closest to her mother, she is most involved in care as well. The elderly women did not have a close relationship with any of her daughters, but two of Rebeca's sisters cannot forgive their mother for how she was. Rebeca thinks her mother was not a bad mother, she was just an independent woman with a special personality. Rebeca describes her mother as an "American" woman, unlike most women in Chile: detached from people and with a special sense of humour.

When her parents divorced after 40 years of marriage, when Rebeca's father left her mother for another women. Following the divorce, Rebeca's mother continued with her life alone. Rebeca felt sorry for her, and that feeling made Rebeca remain close to her mother.

Rebeca's brothers have their own families and problems, she doesn't ask them to participate in the care arrangement. Two of her sisters are actively engaged in their mother's care. The sisters have a messaging group in Whatsapp where they coordinate visits to their mother, and organise help for Rebeca if she has something else to do (e.g. cannot buy a medicine or groceries). The three sisters try to visit their mother daily, to give company to the elderly and to supervise the nurses. They have realised the nurses sometimes ignore their responsibilities and steal medicines or other things.

The dependency path of the elderly woman has been gradual, giving Rebeca sufficient time to adapt to her role as main carer. Rebeca doesn't feel her role as a weight on her life.

Rebeca has always found it difficult to hold a conversation with her mother; and particularly now that her mother has a cognitive deterioration. Her mother was special. She was nice but distant; she had good sense of humour but was only interested in her things. Rebeca notes that before her mother became dependent she could be talking to her about your problems but if she had something more important to think about she wouldn't listen. For this reasons it was difficult for Rebeca to maintain a relationship with her; their relationship was not necessarily difficult, there was practically no relationship.

Rebeca thinks that she and her sisters are going to be like her mother with their own children. She thinks that when a woman has a job and her own world and interests it is inevitable to have that distance with one's children's. And that's Rebeca's case. She has always had high-level professional jobs. She retired a year ago but she stills works as a consultant and wants to continue working for a longer time if her health allows her. Her mother's care is not an impediment for her to develop her professional careers.

For Rebeca, the most important thing about her future as an elder herself is to have enough money so she doesn't have to depend on her children. She would like to travel before losing autonomy. As an elder, she would like to stay at her own place, cared by nurses, like her mother is. Money is an important issue for Rebeca. She thinks it can really avoid conflicts between siblings and make life easier as a result for the elderly.

Rebeca's interview was conducted in her house's terrace. It lasted one hour and she spent a large part of the interview trying to describe her mother's personality. It may be that she was trying to explain why Rebeca has a detached attitude towards her mother and is able to continue with her own life without feeling the pressure of having the role as her mother's main carer.

35. Rita

Rita comes from a middle-income household. She is 55 years old. She lives with her husband, her daughter, her son-in-law and her elderly mother. Rita is the only child and has always lived with her mother; her mother has always been a conservative woman. Alzheimer's completely changed her mother's personality and Rita has had to understand and love a new person, someone completely different from whom she knew. The change in her and her mother's relationship and the loneliness she experiences on a daily basis makes her emotionally vulnerable. Rita spends the day alone in her house caring for her elderly mother. Her only company, other than her mother, are a couple of pets her daughter, a veterinarian, owns.

Before her mother started needing daily help, Rita worked as a saleswoman. She loved her work. She is sociable and enjoys being surrounded by people. Today, her daily life is completely different. Rita works hard solving her mother's demanding care needs. Whenever she has a moment she sits in the sofa and watches television (the television is always on). She does that rarely, though. When she's not providing direct care, she is cleaning, cooking, doing the laundry, etc, and always surveiling her mother.

Coming from a middle-income household, Rita is not eligible – and does not receive –any support for her care work from the government. She neither receives any kind of support from her husband, her daughter or her son-in-law, all of whom live with her and the elder. Her husband, her daughter and son-in-law all work outside the house full time. When her husband arrives home in the evenings, Rita says nothing about her daily routine. She never comments about her feelings towards her caregiving role. She hesitates in asking her husband for emotional support. She claims he wouldn't understand her. For Rita, care is a female subject, and men get bored if they listen too much about care-related issues.

Her faith is important to her; it offers much needed support she is tired and needs to regain strength in the face of her adversity.

Rita used to have an excellent relationship with her mother. They continued to live together when Rita got married and when Rita's daughter was born as well. Her daughter's partner has now joined them in the household. For Rita, her mother was a source of unconditional support; her mother has always been a friend. When her mother developed Alzheimer's, Rita had to learn how relate to an unknown person. It is hard for her to maintain a relationship with her mother like she did before the onset of her mother's cognitive dependency. The contrast between the positive relationship she had with her mother with her current relationship is emotionally very painful. It's not an easy task, the memories of the good relationship they have in the past stain her new relationship, and the comparison between both relationships upsets Rita.

Rita keeps the television on all day. During our interview, I had to kindly ask her to turn the volume down because with the dogs barking and the television on I could barely hear her. She accepted. We had two interviews, both held at her place. Rita cried for a large part of both interviews.

36. Rodrigo

Rodrigo is the main carer of her moderately dependent mother. His mother has no physical autonomy. He lives with her and no one else in an apartment in a middle-income neighbourhood. He is 70 years old; his mother 92. He has a married daughter and a son. They both live independently. His daughter is married and has herself a son. His daughter and her family live in Santiago but in another municipality, a 45-minute commute on public transportation. Rodrigo’s son lives and works close to him and he visits almost every day, they usually have lunch or dinner together. Rodrigo and his son get along well.

Rodrigo is an only child. Rodrigo has always been close to his parents. They have always live in the same community. A few years after Rodrigo’ father death, his mother went to live with his son and his family.

Rodrigo’s wife had cancer and passed away a few months before the interviews. While alive and in good health, she and Rodrigo’s shared his mother’s care. She was in charge of her personal care and Rodrigo of the care management (e.g. making appointments with the doctors, taking her to appointments, managing her pension). Now that Rodrigo is a widow he greatly misses the support he received from his wife. Rodrigo’s father died from cancer 30 years ago. When he was sick, Rodrigo was actively involved in his father’s care as well, supporting his mother who was the main caregiver.

He adopted the role as his mother’s carer because there are no other women in the family available to become the elderly main carer: no sisters, no wife. Rodrigo’s daughter comes at least once a week to help Rodrigo with the elderly woman’s care.. Rodrigo’s son gives emotional support to his father and grandmother and helps his father with instrumental caring tasks.

Rodrigo cooks and does all the home tasks. Rodrigo manages all his mother’s medical appointments. Whenever he needs to set an appointment for her, he wakes up between 4h and 5h so he can be there in person at 6h to set the appointment. On the date for the appointment, he takes his mother to the health centre, a commute involving two buses and the difficulty of travelling with an elderly woman who lacks physical autonomy.

Every morning, Rodrigo exercises to cope with the back pain he attributes to the physical efforts involved in her mother’s care.

He has recently participated in an information-provision programme offered by a University and sponsored by the municipality where he lives. He values meeting nice people who were also main carers of elderly parents and the opportunity to share problems and express emotions. However, after caring for her mother parents for an extended period of time, he also came out of the programme sad, knowing that the things he had been doing to care for his mother care were not necessarily correct. The programme generated guilt, increasing his experience of pressure.

Rodrigo describes his relationship with his mother as a fairly good one. There are moments along the day in which they get mad at each other. Rodrigo says it is because his mother gives him too many instructions on how he should do things. This is especially true for home care tasks because before it was his mother who was in charge before her level of dependency increased. Rodrigo has now taken that role as well.

We had two interviews with Rodrigo, both were conducted in the lobby of the building where he lives. He wanted to have the interviews there so his mother couldn’t disturb us and at the same time he could stay close in case she needed him. During the interviews, his mother called the reception on two occasions to ask Rodrigo how long would he stay out of the apartment. It was difficult to keep the conversation going without talking about Rodrigo's dead wife as he was greatly affected by her death and he still misses her very much.

37. Sandra

Sandra is 42 years old and comes from a low-income family. She is the main and only caregiver of her mother with severe dependency. Sandra came to Santiago at age 18, she grew up in a rural area in the south of Chile. Her mother widowed at young age with 11 young children under her care. Sandra has five sisters and five brothers. She was the last in her phratry to leave her mother; her mother left in the South until she became dependent. Sandra then brought her mother to live with her and her three daughters (Sandra is a single mother). She receives child maintenance allowance from her former husband, the father of her three daughters. This allowance, in addition to her elderly mother's pension constitute Sandra's household monthly income. They are in a financially tight situation. In case of emergency Sandra's male siblings contribute, but this contribution happens only in very rare emergency situations.

Sandra assumed the role of carer without regret, without pressure and driven by the motivation to give her mother a pleasant end for her life after all she had suffered. She argues she cannot share any caring responsibilities with any of her siblings because they are all in paid employment. Sandra does not find this situation unfair, she is strongly motivated to provide her mother's care because she wants to give her a better life in her last years. She has a relatively good relationship with her siblings who help with caring tasks sporadically and give her money if extra costs arise, but it is Sandra who carries the responsibility for all her mother's care, her house and her three daughters.

Sandra adopts her role with satisfaction in spite of the many constraints she faces. The circumstance of why the obligation fell on her and not on her sisters (because, at the time her mother became dependent she was out of the labour market) and her constraints – which could lead to a high intensity of pressure – is offset by her motivation to provide care in determining her feelings towards her care experience.

She believes the most appropriate care for her mother should come from the exclusive dedication of a daughter. She would never pay to someone else to help her with caring tasks, even in the case she had the money. A few months prior to the interview, Sandra received a visit from a social worker from her municipality. The social worker offered her to participate in the Home Care programme and explained that she could have two hours of respite a week. She refused. She gave the social worker an incorrect telephone number so she couldn't be contacted again. Sandra doesn't trust any external caregiver, she prefers to be tired and provide all the care by herself. She also thinks that the best care she can expect to receive in the future is that coming from her own daughters, she prays she does not end up being cared for in a nursing home.

Sandra has a good relationship with her mother. At the beginning of her dependency path and when the cohabitation began, the relationship was harder because her mother had a bad temper and scolded Sandra's daughters. Then have since all learnt to live peacefully and their relationship improved. Sandra has a sad history of violence with her ex-husband. She doesn't want to have a partner again.

The interview with Sandra lasted 1h40 during a sunny summer day, it was held in her home. During the interview, her daughters were at school and her mother was in her bedroom, lying in her bed as she does day and night. Their house was small and tidy. Windows were open and we could hear the birds sing. Sandra spent a big part of the interview crying, showing vivid emotions towards her mother and towards her role as her main carer. She repeated often that she loves her mother and that she doesn't want her to die. Sandra suffers when thinking about her own life once her mother won't longer be with her. She thinks that she might look for a job as a paid elderly caregiver. She thinks that the four years she has been caring for her mother has made her knowledgeable about elderly care and she feels proud because she has learned everything all herself.

38. Sara

Sara is 54 years old. She comes from a middle-income family. She has been caring for her mother for five years. Five years ago, her mother had a stroke which marked the onset of her dependency path. Previously, her mother was independent and lived on her own. She managed her life and daily activities autonomously. After her stroke, Sara's mother had severe dependency. Her and Sara' life changed. Upon discharge after 11 days of hospitalisation, she moved in with Sara and her family. They built a room and a bathroom to receive her. Sara adapted her life as well. She remembers the first months of her caregiving path as the most difficult ones. She fell sick because of the pressure to adjust to her new role as her mother's carer. She used to work full time. She quit her job to, as she says, start a new life in full dedication to her mother.

Sara has currently started working at her house as a pedicurist. Before she worked as a paid carer for elderly people, but she quit because she needed to dedicate herself fully to her mother's need. She has decided to put in practice her pedicure knowledge gained through a course she took when she was young. She works from home as a pedicurist, allowing her to have paid work while still supervising her mother. This arrangement has allowed her to earn some money, be in contact with other persons and have something to think about beyond her mother's care and household issues.

Sara has a brother, but he almost never calls and never helps with caring tasks. She also had a sister who died of cancer ten years ago; Sara was very involved in her care in the past as well. Sara's husband and two children are very supportive and whenever she has to get out of the house, one of them stays at home with the elderly. She has in total three children, the eldest daughter lives independently and Sara cares for her granddaughter in the afternoons when she is out of school and her daughter is at work.

The relationship between Sara and her mother is not easy, especially since they started living together. She feels absorbed by her mother, not because of the amount of time she spends with her but because of the relationship they have. Sara gets mad when her mothers asks her, for example, if she will go to bed soon or when she shouts from her bedroom to ask Sara what she is doing. Sara struggles when her mother, husband and children had plans to go out and at the very last minute her mother decides she doesn't want to go. Sara has to stay with her.

Sara's husband calms her whenever she loses her patience with her elderly mother's care. Sara values that greatly, as well as her husband's kindness towards her mother. Her husband has never complained because of any care related issue, although they have been major changes in their family dynamics and finances, and the fact that Sara's only brother does not provide any kind of support. On the contrary, her husband has always been very supportive. The minor disputes they have once in a while never scale up. Sara can get mad from the fact that no one understands her because no one spends the whole day with her elderly mother as she does. Sara’s husband calms her down and convinces her that her mother has always been that way and that she needs to be patient. After these minor disputes, Sara is grateful of her husband’s patience and kindness.

39. Silvia

Silvia is 52 years old. She became her 84-year-old mother's primary and only caregiver five years ago. Today, her mother has severe cognitive and physical dependency. Silvia lives with her partner and her mother. Silvia has no children. They are a low middle-income household; they have their own house, small and well-cared, with a small and nice garden. Silvia worked as a nanny before being a carer; she hasn't worked for pay since her mother became dependent. Cohabitation started five years ago when her mother's health deteriorated. It was a solution to meet her mother's care needs by being close to her. Cohabitation allowed Silvia to reduce the financial expenses associated to maintaining two households and commuting. Silvia's partner completely agreed to cohabitation. She has a sister who does not participate in her mother's care. Silvia and her sister have a negative relationship.

When Silvia refers to her partner she does so with affection and gratitude, but recognises they are more friends and have lost intimacy. As a result of her mother's care, Silvia is very tired, she does not have the energy to chat or have sex. At night, she puts her head on the pillow and falls asleep immediately. She hasn't taken vacations in years, and her routine is identical throughout the seven days of the week. A doctor or a nurse from the primary health centre comes to do a check-up and exams to her mother once in a while. Apart from this sporadic support, she doesn't receive any social support; Silvia provides direct and emotional care and organises doctor appointments, in addition to the housework.

Whenever Silvia has to go out to buy bread, to get her mom's pension or to buy some groceries, she is constantly worried because she cannot provide surveillance to her mother. She recently met her neighbour Shirley whom stays with Silvia's mother if she has to get out of the house. Silvia can only count on her was asked about the social support she receives.

Silvia's health has also deteriorated. She is undergoing medical exams to discover her ailment. Doctors think she might have breast cancer, but they are waiting the results of the biopsy for confirmation. Silvia's major concern now is not to die before her mother.

Silvia's experience as carer has many constraints. She has a limited financial situation, a bad health condition herself and has a small social network she can count on for support. However, Silvia experiences her elderly mother's care as emotionally rewarding. She appreciates the opportunity to caring for her mother. Silvia loves her mother and she is grateful of how her mother was with her throughout her life.

Silvia and her mother have always had a positive relationship. Silvia thinks about herself when she was a baby and her mother changing her diapers when she changes her mother's. It is a very sensitive issue and emotional disturbing for her. She cried during the interview when she referred to these intimate tasks. Seeing her mother without the ability to go to the bathroom by herself symbolises her health deterioration, which makes her sad.

Silvia never thinks of combining caregiving with a paid job. She is happy dedicating her entire life to her mother. Caring for her mother is a decision Silvia made. Her main motivation is to give back for what her mother did for her in the past.

For Silvia, the beginning of the caring path was the most difficult stage, because she didn’t feel prepared to care for her mother. When Silvia decided to bring her mother to her house and become her main carer, the elderly mother already had an advanced level of physical and cognitive dependency.

Two interviews were conducted with Silvia. In the first one she looked very serious and rigid. Little by little she started to open her heart and soften her face’s expressions. She ended up crying many times along the interviews, particularly during the second one.

40. Trinidad

Trinidad is 62 years old. She is the main carer of her severely dependent 98-year-old mother. She also cares for her 68-year-old brother diagnosed with Parkinson's disease. Both her mother and her brother live together with another brother (the eldest), a 20-minute bus ride away from her home. She goes there on a daily basis, arriving at 1pm and leaving at 9pm to join her husband at their own place. A paid carer comes in the mornings to help her. The paid carer changes the elderly mother's diapers and does some cleaning.

Trinidad is one of eight siblings. The eldest brother – who lives with Trinidad's mother and dependent brother – sometimes helps in the care arrangement, by putting in money or helping with tasks that require physical force when Trinidad can't do it anymore. Trinidad is physically tired because of the strength she has to put in when caring her mom. The other six siblings, three men and three women, only cooperate financially with money. Trinidad is in a big fight with her sisters for not providing her support with caring tasks. She never refers to any type of conflict with her brothers who, like her sisters, don't contribute to caring tasks. Although there is no legal duty in Chile to care for an elderly parent, she found a lawyer, sued her sisters for the lack of support, and went to the court.

Trinidad does all caring tasks. Providing intimate care, for her, is like dealing with a very fragile human being. It symbolises how much her mother has changed in the last months and has became a different person. Giving medication to both her mother and her brother is also an important part of her daily routine. She pasted the medicine schedule in the middle of the living room so that neither she nor the morning paid carer forget.

During the summer vacations, Trinidad is also the main carer of two of her grandchildren. She takes care of the children while also caring for her mother and dependent brother. Trinidad enjoys caring for her grandchildren, it gives her energy for the rest of her daily responsibilities. The rewards from childcare offset the pressures of elderly care for Trinidad. She enjoys helping in her grandchildren's development and watching them learn and grow. When she talks about her mother's and brother's care she shows tiredness and frustration; when she talks about her grandchildren's care her eyes shine and a slight smile appears on her face.

For Trinidad her multiple caring responsibilities are not a constraint. While being her elderly mother's carer is a source of pressure, being her grandchildren is a source of pleasure.

Trinidad lived with her husband when her mother started needing help on a daily basis. Her mother lived with two of her sons and a daughter-in-law but it was Trinidad, being the female sibling available, who became the main carer. For the first months of the care arrangement, Trinidad commuted daily to her mother's place (20 minutes by bus). She then decided to move and live with her mother to avoid the commute and be available for her mother day and night.

Trinidad's husband stayed alone at their place. Their marriage relationship was damaged by this residential arrangement which lasted for four years. Trinidad then realised she needed her own space. A doctor had found her depressed and suggested she takes some distance from her caregiving role. Trinidad also needed to be closer to her husband who was also getting older and needed company and more help in daily life activities.

Trinidad struggles with the physical fatigue of caring for both elderlies all by herself, but she also struggles with the anguish of seeing her mother abandoned by the rest of her children during the last years of her life. For Trinidad, her mother had a very good relationship with her younger daughters and gave everything to them, much more than what she gave to Trinidad, because they are younger and by that time her mother had a better financial situation than the one she had when Trinidad was young.

Trinidad remembers her childhood as one full of sadness and loneliness. Her father was an alcoholic and was never at home. Her mother was dedicated to raising the younger children and was abusive to Trinidad, both physically and psychologically. When Trinidad was eight years old she had to work to contribute money to the household. When Trinidad was a teenager, she got pregnant and her mother kicked her out of the house. Trinidad came back when she was in her thirties. At that time, Trinidad became a member of the Communist party. When her mother found out, she feared that the military government would harm the whole family, and kicked Trinidad out of the house for a second time. Trinidad has never had rancour towards her mother. Every time her mother opened the house for her she was ready to come back.

The largest difficulty for Trinidad is not her physical fatigue and the postponement of many aspects of her life by dedicating herself to caregiving. The largest difficulty lies in the sadness and anger she feels seeing that no one else cooperates with the elderly care and the subsequent relationship she has with her sisters. Trinidad's deepest constraints are rooted in a context of relationships marked by a difficult life history. Trinidad suffers the most from the relationship with her sisters. Trinidad understands the difficulties her mother faced along her life that explain the fact that she was not a good mother with her. The relationship with her sisters is different. Trinidad cannot understand why her sisters have basically run away from her mother now that she needs care, particularly given that she was a good mother to them.

Appropriate care for Trinidad is one equally shared among siblings. She brought her care ideal up to court, even though there is no legal obligation that states that elderly care should be shared among the phratry.

41. Victoria

Victoria is 45 years old and the main carer of her 90-year-old mother-in-law. They belong to a low medium income household. Victoria has two school age children. Her husband is the only child. Victoria, her husband and children have lived together with the elderly women for 10 years. Victoria has been the main carer, caring day and night, for two years. The two women currently have a positive relationship, which follows the positive relationship they have always had.

Victoria's biggest difficulties in caring for her mother-in-law are the financial constraints they face as a family, together with their social isolation and loneliness.

Victoria does not count on her husband for any support except for financial support. Caregiving is her own and sole responsibility, even if she carers for her mother-in-law.

She feels her husband does not understand her situation. She once tried to talk to him about her worries and feelings, how she was tired and felt sad. Her husband reacted badly; he didn't understand and misinterpreted Victoria's feelings, proposing her instead to take the elderly to a nursing home if care caused her too many problems. Victoria was just trying to find relief and understanding after a hard day. Since that event, she has never tried talking to her husband when she is sad, tired or worried. She justifies her partner's lack of support by saying that he, and men in general, already has his own problems.

Victoria used to hold multiple jobs before becoming her carer. She stopped working after her mother-in-law's dependency level increased and none of her employers allowed her to combine paid work and care. Recently, her household began needing a supplemental income source and she began searching for a part-time job. A part-time job was her preference as she did not want to leave her mother-in-law alone all day. Though she landed some interviews, her search was unsuccessful. None of the possible employees accepted that she work part-time. It has been almost a year since she began looking for a job; she hasn't found one that allowsher to combine work and care.

One interview was conducted to Victoria. She looked tired and cried throughout the interview. Her mother-in-law, in a wheelchair, was in her room, next door to where we met. At the end of the interview, I visited the elderly in her room, she looked nice and quiet; she smiled and was friendly. Victoria hugged her mother-in-law when I asked for their permission to take a picture of them.

42. Violeta

Violeta is 62 years old. She is an only child. She has been given care to her 86-year-old mother who has a cognitive dependency for five years.

Violeta lives with her mother and husband since the elderly began needing care. They live in a modest and beautiful house, with plenty of natural light, a well-cared garden and six pets (two dogs, a turtle, one cat and a pair of birds in a cage). Violeta has a married son and a grandchild. She comes from a medium income household and she considers her financial situation as "a good enough situation that allows living without financial worries." She retired from work five years ago, after having worked for 40 years as a secretary in a government agency.

She has a good marriage though they are now like friends because she puts most of her energy caring for her mother, they have lost intimacy. Violeta's husband is supportive. Violeta values her husband's emotional support and the patience he has with the care situation. She appreciates his patience and support, because it comes despite the lack of time they can spend together and the bad humour she has. Violeta's caring role causes her a daily and heavy feeling of pressure; her husband is always providing her with emotional support and she appreciates it. She has a good relationship with her son and his wife. She loves her granddaughter and she sees her once a week. She doesn't have time to see friends but she takes part in a weekly knitting club (meetings are at her house) where she gets to meet nice people. She lives in a municipality that provides a wide variety of services for the elderly and retired people. A doctor in the primary health care centre sees her mother often. Violeta trusts the doctor.

For Violeta, her faith in God offers a strong support.

Violeta has a low level of constraints in her life, when compared to other carers. However, she experiences a strong feeling of pressure on an everyday basis. She recognises her situation is supposed to be a good one due to the lack of constraints and favourable situations, but she still finds caring for her mother extremely difficult. Her difficult past relationship with her mother weighs heavily, making her experience care intensely and with difficulty.

She has had a historically tense relationship with her elderly mother, and she is not happy being her mother's full-time carer without any form of respite. She feels a strong moral obligation to be her mother's carer because she is an only child and no one else is available. Violeta, worked her whole life and was looking forward to retirement to have free time and travel. She sees caring for her mother as an obstruction to her original plan. She had saved money for traveling, but she remodelled her house instead as traveling is not an option while caring for her mother.

Ideally, Violeta would like to delegate care to an external caregiver for a couple of hours a day. Financial constraints limit her possibility to externalise care. This distance between her ideal of care and the current situation, together with the difficult past relationship with her mother imply that she does not have a good experience of care. She struggles and assumes her role as the main and only carer with pressure.

Violeta would feel guilty if she sent her mother to a nursing home. It is her role to care for her mother. She believes that elderlies don't live long in nursing homes because they receive a very low quality of care. Although she experiences her role as her mother carer with high pressure, leaving her mother in a nursing home would replace the intensity of direct care with guilt, not necessarily reducing her feelings of pressure.

When she becomes dependent, Violeta doesn't want to live in a nursing home. She is afraid of her future as an elderly in need of care.

For Violeta, her age is a constraint of her carer role, because it symbolizes that in caring her mom she is losing energy and time that she wanted to spend leisure activities or traveling. No that she has the energy and good health to do that.

The historical bad relationship with her mother comes up every day in different situations. Although they have now a very different relationship because of her mother cognitive disease, the past weights too heavy on Violeta's daily life.

For Violeta, bathing her mother is the primary expression of her mother's frailty and dependency; issues that she still has troubled assuming.

Two interviews were conducted with Violeta. She was very open and willing to share her emotions and past life. The second interview was an opportunity to get deeper onto the relationship Violeta has with her mother in the past as to understand her strong feelings of pressure in the present.