The University of Sheffield

‘*Keeping Things in Balance*’: Family Experiences of Living with Alzheimer’s Disease. A Constructivist Grounded Theory Study

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Nuria Esandi Larramendi

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ABSTRACT

Alzheimer’s disease (AD) is a chronic and incurable condition that results in progressive cognitive decline and increasing dependence for the affected individual. However, its impact is not limited to the individual but extends to the family who usually have a fundamental role in providing support. Traditionally research and policy on Alzheimer’s family care has been largely focused on dyadic relationships and the experience of burden and stress, providing little understanding of the complexity and reciprocity of the caring dynamic within the family unit as it unfolds over time.

Adopting a family systems approach and a constructivist grounded theory methodology this study explored the experiences of living with AD for native Spanish families. Data were collected from a series of 26 interviews with seven family units living with early stage AD and three focus groups with 14 caregivers of people with mid-advanced AD. Data were analysed to capture the main processes involved and charted how these evolved over time.

Three main temporal stages to the early AD experience were identified termed *‘what’s going on here’*, ‘*our life is changing’* and *‘keeping things together*. These developed in an iterative rather than linear fashion. This model and the processes that shape the experience (‘noticing’, ‘watching’, redefining’ and ‘balancing’) reinforce the evolutionary and dynamic nature of living with early AD. The data strongly suggested that the nature and quality of existing family relationships and interactions are significant factors influencing the experience of AD for all members. The findings highlighted the impact that AD has on family dynamics and how these shape family responses to living with this condition. Some family dynamics were and remained close, others had always been and remained conflicting, some dynamics remained constant whilst others changed. A major finding of the study was the lack of professional support that all families experienced leaving them ‘feeling abandoned’.

The study provides valuable new insights into the nature of family relationships when living with AD, the impact the condition has on family dynamics and the ways in which family works to keep things in balance in the face of uncertain and constantly evolving challenges. Implications for policy, practice, education and further research are considered.

ACKNOWLEDGEMENTS

Firstly I would like to pay tribute to the family participants in this study, who invited me into their homes, and willingly gave their time and knowledge, shared their particular stories and experiences and taught me so much. Without their involvement, cooperation, reflections and constructive feedback this study would not have been feasible and completed.

I would like to express my deepest gratitude to my supervisors, Prof. Dr. Mike Nolan and Dr. Ana Canga for their encouragement, endurance and expert advice throughout this learning experience. Thank you for questioning my work and guiding my reflection. Although at times the process was arduous, I have learnt that reflection is the way for positive change.

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Thanks also to all my colleagues, classmates and friends who have supported me along the way and given me encouragement, valuable comments and help throughout the study period.

Finally this study and thesis would not have been completed without the absolute support and understanding of my family over the last few years. My sincere gratitude is also extended to them, who have served as a stimulus to continue and persevere in my work.

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LIST OF ABBREVIATIONS

AD	Alzheimer’s Disease
WHO	World Health Organization
UN	United Nations
ISSA	International Social Security Association
INE	Instituto Nacional de Estadística (Spanish Statistical Institute)
IMSERSO	Instituto de Mayores y Servicios Sociales de España (Older People and Social Services Institute)
BOE	Boletín Oficial del Estado (Official State Gazette)
ADI	International Federation of Alzheimer Associations
CEAFA	Confederación Española de Asociaciones de Familiares de personas con Alzheimer y otras demencias (Spanish Federation of Alzheimer Associations)
AFAN	Asociación de Familiares de Enfermos de Alzheimer de Navarra (Alzheimer Association of Navarra)
LTC	Long Term Care
ADLs	Activities of Daily Living
APA	American Psychiatric Association
DSM-IV	Diagnostic and Statistical Manual of Mental Disorder
NINCDS-ADRDA	National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer´s Disease and Related Disorders Association
MMSE	Mini Mental State Examination
CMSA	Case Management Society of America
GT	Grounded Theory
CCM	Constant Comparative Method

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INTRODUCTION

Alzheimer's disease (AD) is a chronic and incurable condition that results in progressive cognitive decline and increasing dependence for the affected individual. However, its impact is not limited to the individual but extends to the family who usually have a fundamental role in providing support. Moreover, this disease also affects society as a whole and requires investment in identification, protection of vulnerable individuals, health and support services. To address these challenges Alzheimer's care requires a holistic, interdisciplinary, multiprofessional and multisectoral approach that ensures the right level of support and care to the person with AD and the family, safeguarding the interests of all concerned. This means recognizing the value and identity of the person with AD and improving their quality of life, whilst acknowledging the same for the family. Consequently, care services should focus more on the experience of the person with AD and their families rather than the condition itself.

Traditionally, the focus of prior research has been on the caring dyad. This has resulted in a limited understanding of the impact of AD on family structures, family members' relationships and interactions over time (Peisah, 2006; Keady and Harris, 2009), failing to recognize that AD may alter the 'normal' structure and dynamics of a family. Likewise, changes in communication patterns, relationships between family members and family roles may influence the way in which families perceive their new situation and the meaning they attached to care. This may justify the need for a family system approach and therefore an inclusive view of family in AD's care. The family system approach used in this study considers the family as a unit and not just as the sum of its members; it concentrates on both the person with AD and the family simultaneously (Wright and Leahey, 2009), and seeks to understand the interactions and reciprocities that occur as the family lives with AD over time. This approach may help to better understand the meanings that the family attributes to living with AD, the relationships established between them, and those aspects that reduce negative consequences and promote positive feelings.

Qualitative research and specifically grounded theory (GT) are suited to the above purposes as it explores perceptions and meanings that people have regarding a phenomenon (Taylor and Bogdan, 1998) and the social processes that occur (Harmon et al., 2005; Charmaz, 2006).

As well as adding to theory it is hoped that this study will provide new insights that may help inform better services and support for families caring for older people with AD and develop new strategies built on family strengths and resources. This in turn should lead to changes in service systems so that there is a better balance between support for the person with AD and the wider family unit over time.

This introduction begins by considering my motivation for selecting the subjective experience of families living with Alzheimer's disease, including the older person with Alzheimer, as a focus for my Ph.D. study, and describes some of my previous experiences and understanding about the research topic. It then provides an overview of the content of thesis and outlines each of the chapters.

Personal Motivation for Undertaking the Research

I gained my Bachelor's degree in 2007 at the School of Nursing of the University of Navarra (Spain), and worked for a period of time as a (general) nurse in the Oncology and Haematology area of the University Hospital of Navarra (CUN). Between 2007 and 2009, I undertook a two-year master's programme in Nursing Science at the school. This was focused on the development of both advanced nursing practice and research competences; therefore it allowed me to acquire skills in research, decision making, organization and planning as well as to gain experience of university teaching.

For that purpose I obtained a research fellowship from the University of Navarra Business Foundation. This allowed me to carry out my master's level studies as a research and teaching assistant at the Department of Nursing Care for Adult Person. Dr. Ana Canga, who had particular research interests in Gerontological Nursing and Family Nursing, was my mentor during that period of time. She introduced me to the academic and research activities in the Department, specifically in the area of older people. I worked with undergraduate students, who developed their clinical practice with older people in nursing homes, which allowed me to stay in close contact with every-day clinical practice in these particular settings. I also worked extensively with her on the development of Geriatric Nursing, later called ‘Nursing Care for Older People’ (2011- present). As a result I developed an interest in both Gerontological Nursing and Family Nursing that I have pursued ever since.

Following my Master degree I continued working at the School of Nursing and particularly in the area of older people.

During this time Prof. Mike Nolan gave an inaugural lecture to celebrate the creation of the María Egea Chair, an initiative promoting the University of Navarra's role in seeking nursing best practices. He shared his work on the needs of frail older people, especially those with dementia, and their families in both community and nursing-home environments, and how family and formal carers may work together more effectively. In particular I was impressed by his work on the application of relationship-centred care to enrich the family caring experience and the development of a more comprehensive approach to the concept of family care. This made me decided to undertake my Ph.D. studies at the University of Sheffield focusing on dementia family care in Spain.

My Ph.D. studies, both at the University of Sheffield and the University of Navarra, provided me with extensive opportunities to expand my knowledge in the nursing and health-care field and learning, allowing me to develop and improve my skills in research including international visits: participation in the three year programme of summer school for doctoral nursing studies of the European Academy of Nursing Science (EANS) between 2011 and 2013; and a visit to the School of Nursing at University of Sao Paulo in Brazil in 2014 through the Santander Research Mobility Award. This provided me the opportunity to meet Dr. Margareth Angelo, one of the leading authorities in the Family Nursing field in Latin America, and participate in different research seminars and group work with the Family Nursing Studies Group, which she is head of.

There are also personal reasons why I was particularly interested in exploring family experiences of living with AD. My grandmother and my whole family have been living with AD for about thirteen years. It was during the latter years that I realized how my family situation had changed over time (with gains and losses), and the limited professional support, especially in the early stages, that we received. My personal experiences highlighted the impact that living with the condition has on the whole family unit and how little family support is available in the Spanish context.

In Spain the family has a fundamental role in providing care for dependent people (Esparza, 2011; Canga and Vivar, 2013), and it is estimated that about 85% of such care is provided by relatives. At the same time current societal changes such as, an increasing ageing population and changes in family structures and lifestyles are challenging the provision of family care and the sustainability of this model (IMSERSO, 2005; Canga et al., 2011). Society is facing a paradoxical reality; while there is an exponential increase of care requirements, the opportunities to attend to them within the family context are declining (Ministry of Labour and Social Affairs, 2005).

Strategies and programmes to support family care are being developed and implemented nowadays; however most of them are primarily focused on the instrumental aspects of care and are mainly motivated by economic and pragmatic concerns (Ward-Griffin and McKeever, 2000). Consequently, services often do not meet the less obvious needs of families who often have little support.

Therefore both my academic background and personal factors provided the major motivation behind this study, which, I hope will only to add to understanding about how families live with AD, but to also generate insights that might improve the support they receive.

Having briefly discussed my reasons for conducting the study I now outline the structure of the thesis itself.

Outline of the Thesis

The first chapter following this introduction sets the scene through an exploration of the current ageing population and approaches to long term care. This contextual chapter addresses demographic trends worldwide, in Europe and Spain, followed by a general overview of the epidemiological transition that occurred during the 21st century. The implications that ageing, chronicity and dependence have for society, particularly in social and health fields, are also addressed. Chapter two provides a general overview of the dementia syndrome, emphasizing the Alzheimer's type as being the most prevalent form of dementia and the focus of this study. This is followed by a discussion on the increasing importance of dementia and AD in public health area. A summary of the main international policy initiatives in dementia is presented, concluding with the current state of art in Spain.

Chapter three considers the literature on the role played by the family in supporting people with AD. This is not a systematic critique of existing work but rather a thematic overview of prominent issues about the family experience of living with AD at the time the study commenced, in order to identify sensitising concepts that informed the initial course of the study.

In chapter four, the methodology underpinning this constructivist grounded theory (GT) study is described including the rationale for selecting qualitative research, considerations informing the use of a constructivist GT approach, important methodological issues, the constructivist GT study process and its application, theoretical sampling decisions, data collection procedures and analysis methods, quality criteria for the study and ethical considerations.

In Chapter five and six the major findings of the study are presented, describing the socio-demographic characteristics of participants and a case study of each of the participating families, finally presenting the temporal three stage model developed on the subjective experience of families living with AD.

In Chapter seven, a reflexive account of methodological issues affecting the quality of the study is presented, following Charmaz's quality criteria for GT studies. Finally Chapter eight offers a discussion of the findings relative to the study aims and the existing literature. Additionally recommendations for further research are discussed, and the implications for practice, education and policy are considered.

CHAPTER 1

DEMOGRAPHIC AND EPIDEMIOLOGIC TRENDS IN 21ST CENTURY: CHALLENGES FOR AN AGEING SOCIETY

Introduction

Population ageing is occurring in nearly all the countries of the world. Low fertility rates, along with an increase in life expectancy and greater numbers of people entering advanced old age have contributed to this phenomenon. Longevity is regarded as an achievement of modern society, in part due to factors such as the success in dealing with childhood diseases and maternal mortality, scientific and technological advancements and the adoption of better life styles. Nevertheless population ageing presents both opportunities and challenges (WHO, 2013).

Living longer increases the risk of developing long-term conditions, which often increase dependency, and require greater familial and societal support, especially when dealing with conditions such as dementia (Beard et al., 2012). Current demographic and epidemiologic trends impact on finances, policy and social security systems in all countries (IMSERSO, 2008; ISSA, 2010; Beard et al., 2012). The particular interest here is the impact on health care systems and the family, as major social institutions.

The following chapter charts such influences. Firstly it outlines demographic trends worldwide, in Europe and Spain, followed by a general overview of the epidemiological transition predicted for the remainder of the 21st century. The implications that ageing, chronicity and dependence have for society, particularly in social and health fields, are addressed.

1.1 Current Demographic Trends: Population Ageing

Recent decades have witnessed unprecedented demographic changes, characterized by a rapid increase in the proportion of older people, commonly known as population ageing. This worldwide phenomenon started in the twentieth century and has been a progressive trend affecting all countries, although the rate of change has varied (WHO, 2013).

The proportion of people aged 60 and over is growing exponentially compared to other population groups. Between 2000 and 2050, the proportion of the world's population over 60 years will double from 11% to 22%. The absolute number is expected to increase from 605 million to more than 2 billion over the same period (UN, 2012; WHO, 2013). While the numbers of children and young people will also increase, this will not be as significantly as growth in the older population. However this increase will not be uniform, with the greatest growth in numbers being in those aged 80+. Currently the population aged 80 years and over accounts for 14% of the ageing population but it is expected that by 2050 this will rise to the 20%. The number of centenarians is also growing, and it is projected to increase tenfold, from roughly 343,000 in 2012 to 3.2 million by 2050 (UN, 2012).

This population ageing is due to the interplay of three main factors:

- Firstly the reduction in the younger population due to a *falling birth rate*. The world's total fertility rate has declined abruptly from 5 children per woman in 1950 to roughly 2.5 at present, and it is expected to drop to about 2 by 2050 (Beard et al., 2012). In Europe this rate is currently estimated below 1.6 children per woman. Although a slight increase in fertility was evidenced between 2000 and 2009, it remained below the calculated replacement level of 2.1; this being the level that would keep the size of the population constant in absence of inwards or outward migration (Eurostat, 2013). According to the Spanish Statistical Office (INE, 2013) the number of births in Spain will continue decreasing, following the trend started in 2009. It is estimated that around 3.9 million of children will be born between 2013 and 2023, which is 17.1 % less than the previous decade.

Consequently as families have fewer children the older age groups will naturally increase.

- Secondly people are living longer as *life expectancy continues to increase*. Globally, life expectancy has increased by two decades since 1950 (from 48 years in 1950-1955 to 68 years in 2005-2010), and is expected to rise to 75 years by 2050 (Beard et al., 2012). Although there are still substantial differences between developed countries, at 82 years, and developing ones, at 74 years, this gap has narrowed significantly in the last decades. Currently life expectancy for the EU-27 is about 77.4 in males and 83.2 in females (Eurostat, 2014). Differences among Member States are still very significant, ranging from almost 12.6 years for men to 7.8 for women (Eurostat, 2014). Life expectancy at birth in Spain is expected to reach 81.8 years in males and 87.0 in females by 2022, resulting in an increase of 2.5 and 1.9 years respectively, compared with 2014 values. Likewise, the life expectancy of older people is increasing rapidly (INE, 2013).

- Lastly there has been a *gradual reduction in mortality*. In the early phases of this demographic transition, large cohorts were born, mainly because mortality, especially among infants and children was high. This has decreased and these larger cohorts are nowadays reaching retirement age (Beard et al., 2012).

People aged 65 and over represent significant numbers in all European countries. Data from the Eurostat report on the first quarter of 2014 revealed an EU-27 population of 505.70 million inhabitants of which around 90 million were aged over 65, accounting for 17.8% of the total population. Future projections suggest a significant increase of this cohort, reaching 151.5 million by 2060 (UN, 2007). Along with this exponential growth in the older European population the most significant change is in the numbers of the ‘oldest old’. The number of European inhabitants aged 80 years and over is projected to almost triple from 23.3 million in 2010 to 61.4 million in 2060 (ISSA, 2010).

Spain is experiencing similar trends to the rest of Europe. Older adults made up 17.7% of the total population in 2013; with 8.3 million people aged 65 and over, a rise from 5.2% at the beginning of the 20 century (IMSERSO, 2009). This is set to continue. By 2023 there will be 9.7 million people aged 65 and over, representing 22% of the total population. In particular there will be a significant increase in the proportion of people aged 85 and over, who will by then represent 17.5% of the ageing population. In addition it is expected that 23,428 persons will reach the 100 years old by 2023, nearly twice the current number (INE, 2013). As a result the Spanish population is increasing in the upper half of the population pyramid.

In the Autonomous Community of Navarra, in which the study was undertaken, ageing is above the national figure, at 18.14%, which means 116.914 people aged 65 and over in a population of 644.477 inhabitants (Navarra Statistical Office, 2013). The group of people aged 80 are also above the national average at 2.95% of the total population compared to 2% nationally. Navarra is the Spanish region with highest life expectancy at birth in males, at 81.1 years, and the seventh position in females, at 86.5 (Navarra Statistical Office, 2013).

Although population ageing is considered a success for modern societies, it brings with it an increase in long-term conditions and associated dependence (Canga and Vivar, 2013). Dependence, usually referred to *'need for care'*, is defined as *'the need for frequent human help or care beyond that habitually required by a healthy adult'* (Prince et al., 2013, p. 4). According to Guillén and Bravo (2008), disease prevalence and incidence are notably higher in advanced old age, together with chronicity, disability and dependence rates. Hence, as people get older the incidence of morbidity and mortality increases.

In Europe the old-age dependency rate is estimated at 27.5% (Eurostat, 2013) and the Spanish figure will increase from the present 27.6% to 35.1% by 2023 (INE, 2013). In addition to this, the family support rate (the number of people aged 85 and over per 100 people aged 45 to 65 years) has been progressively increasing over the last period and it is estimated that this trend will continue, reducing the family support available (Ministry of Health, Social Services and Equality, 2012). This has implications for societal support as a whole.

1.2 Epidemiologic Transition: Long Term Conditions and Dependence

Alongside population ageing an epidemiological transition has occurred, with a shift from a predominance of infectious diseases and high maternal and infant mortality towards a growth in the numbers of people living with long term conditions[1] (WHO, 2012). Therefore the current dominant epidemiological model is characterized by chronic non-communicable diseases. Syndromes such as diabetes, asthma and dementia are much more prevalent. In 2011, 32% of the EU-28 population aged 16 years and over reported suffering from a chronic illness or long-standing health problem (Eurostat, 2013). Age was the most significant factor since only 10% of the population between 16 and 24 years old declared having a chronic health problem while the figure was about 70% for those aged 85 years and over (Eurostat, 2013).

In accordance with data from the European Health Interview Survey (2009), about 46% of the Spanish population aged 16 and over years suffered from a chronic condition, and 22% experience co-morbidity. This figure rises among the oldest population segment. People ranging 65 to 74 years old had an average of 2.8 chronic disorders, increasing to 3.23 in people over 75 years.

Ageing implies changes in physical and cognitive reserves that may lead older people to be at risk of greater morbidity and functional limitations than the young (Fried et al., 2001), although this does not always imply suffering from a long term condition. Greater longevity means that, people may live more productive years and more years suffering from chronic diseases and co-morbidities, and dependence (Beard et al., 2012). So this in turn may imply both economic benefits and costs to society.

Worldwide chronic non-communicable disorders are, by far, the leading cause of mortality, representing 60% of all deaths in the world (Anderson, 2004) and 86% in Europe (Eurostat, 2013). Moreover, they have been recognized as the predominant contributor to disability and dependence (Verbrugge and Jette,

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[1] *'(...)life-long and gradual progress conditions that cause premature death, involve some limitations on the quality of life of people affected, generating significant economic, psychological and social effects on families, communities and society'* (Ministry of Health, Social Services and Equality, 2012, p.20).

1994; WHO, 2012; Prince et al., 2013). By 2008, the burden of non-communicable diseases, measured by the loss of healthy years, already accounted for an estimated 86% and 37% in developed and developing countries respectively. Among the older population these conditions currently entail 87% of the burden (WHO, 2012). According to data extracted from the report on *Dependence Assessment in the Community of* Navarra (Zugasti, 2013), conditions such as Alzheimer's disease, polyarthrosis, cerebrovascular disorders, and Parkinson highly contribute to severe and extremely severe dependence.

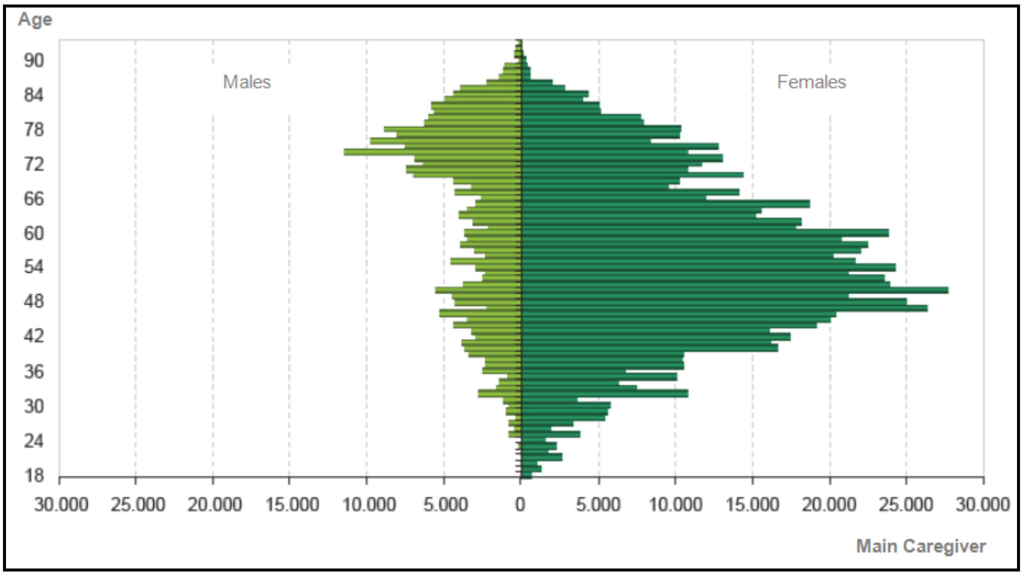
Worldwide, the total number of dependent people will nearly double from 349 million in 2010 to 613 million in 2050. Furthermore, the number of older people who need care will nearly treble from 101 to 277 million during the same period (Prince et al., 2013). According to data provided by the last *Survey on Disability, Personal Autonomy and Dependence* of the Spanish Statistical Office (EDAD, 2008), 8.5% of the Spanish population (3,847,854 people) has some kind of disability or limitation in activities of daily living (ADLs); of which 55.8% (2.148.548 people) are people with a level of dependence that require someone to support them (IMSERSO, 2008). Most of this support comes from the family**.**

1.2.1 Family Care and Older People

Whilst the family has a key role in supporting frail older people worldwide this is especially so in Spain, where it is estimated that about 85% of this care is provided by relatives, who are predominantly female (Puyol and Abellán, 2006; Hoffman and Rodriguez, 2010), generally in their fifties and with primary or lower education. However male caregivers are increasingly common at advanced ages, as Figure 1.1 Illustrates (IMSERSO, 2008; Esparza, 2011).

Although the family remains central to supporting frail older people current societal changes such as, increasing ageing population and changes in family structures and lifestyles, are challenging the potential of family care and the sustainability of this model (IMSERSO, 2005; Canga et al., 2011). Society is facing a paradoxical reality; while there is an exponential increase of care requirements, the opportunities for family support are declining (Ministry of Labour and Social Affairs, 2005).

Figure 1.1 Number of primary caregivers of people aged 65 and over by 2008



Source: Esparza C. (2011) ***Discapacidad y dependencia en España*****. Madrid: Informes portal de mayores, 108, p.6.**

However older people, even those who require care, may bring rewards to the family. Living with and caring for older relatives may provide an excellent educational opportunity for the young and favourable circumstances to strengthen emotional ties between generations (Rivas, 2013). Family solidarity, for instance, is considered an expression of the *'vertical family'* (Abellán and Esparza, 2010). The family provides care and sustenance to its older relatives while these in turn grant important social support by integrating offspring into the labour market, taking care of their grandchildren and providing financial support, advice and assistance to younger generations. Therefore the coexistence of several generations can positively impact on shared social capital (Bengtson, 2001; Rivas, 2013).

Preserving the sustainability of family care requires policies and services that complement the family's efforts based on partnership working (Nolan et al., 2008; Hoffman and Rodriguez, 2010; Canga, 2011) to enable them to continue caring for their loved ones for as long as possible in a appropriate and sustainable manner. Recently several authors (Lloyd-Sherlock et al., 2012; Beard et al.,

2012) have argued that future social policy should challenge paradigms and social attitudes related to ageing and prepare health-care providers and society as a whole to meet the specific needs of this population by taking actions such as: i) including professional training on ageing care, prevention and management of age related chronic diseases; ii) designing particular policies on long-term and palliative care; and iii) developing age-friendly services and settings. As has been suggested by Carstensen and Fried (2012):

> *(…) if we play our cards right, prolonged lives can allow us to redesign them in ways that improve quality at all ages and across generations. The gift of time we received from our ancestors in the 20th century present us with unprecedented opportunities. To be sure these opportunities will be missing if we do not begin to prepare for them. The real challenge, as we see it, is only partly about finding ways to care for dependent elderly. Aging societies will success or fail largely as a function of the new meaning we ascribe to both healthy and unhealthy longer lives* (p.15).

1.3 Meeting the Challenges of an Ageing Population, Long Term Conditions and Old-Age Dependence

In most industrial countries health care systems have traditionally been oriented to the acute treatment of certain disorders, especially related to children and the younger adult population, a model that has failed to address the needs of an increasingly frail ageing population (Prince et al., 2013). Recognizing this failure the WHO (2005) developed a reference document *Preventing Chronic Diseases, a Vital Investment* that challenged health care systems worldwide to revise existing care models and implement appropriate and effective interventions to address chronicity and LTC.

In 2010 the Council of the European Union issued a series of conclusions with regard to the development of national action plans in reducing the impact of chronic diseases in Europe, all of them contained in the *Innovative Approaches* *for Chronic Diseases in Public Health and Healthcare Systems* report (The Council of the European Union, 2010). The Council called Member States to develop person-centred policies for health promotion, primary and secondary prevention, treatment and care of chronic diseases, in collaboration with policy makers and especially with relevant disability associations.

In response to this Spain released *The Strategy for Addressing Chronicity in the NHS'* in 2012 (Ministry of Health, Social Services and Equality, 2012). This provided goals and recommendations for a change of focus in the Spanish healthcare system in which care is more people oriented, targeted at community and individual levels, and in which personal autonomy promotion is emphasized.

As a result of the demographic and epidemiological changes, the Spanish NHS has had to respond to a growing demand on services and increasingly diverse needs, with a consequent increase in health care and resource utilization. However, health care services have traditionally focused on addressing acute problems through episodic care plans, with a curative approach (biomedical model) that underestimates preventive strategies and population empowerment. Furthermore, a lack of coordination among different levels of care as well as between health and social services is still one of the main causes of inefficiency in the provision, development and management of available resources and services. What is needed is a strategy based on interdisciplinary teamwork, between health professionals and social services, continuity of care and the maximum participation of those people affected (Government of Navarra, 2013).

Community health care professionals often have direct and sometimes frequent contact with people affected and the families who care for them. Hence they are in an ideal position to closely assess and monitor the impact that both the condition and the care experience have for the person and the family. Such understanding is essential to develop services and support programs targeted at both the frail person and the family as a whole including emotional healing, building on family strengthens, promoting satisfaction in care and preventing family complications.

1.3.1 Family-Care Support Policies

In the past 20 years the importance of family care of dependent older people has become recognised in a European context. In the early and mid-1990s a series of studies, conducted with the auspices of the European Foundation, highlighted the fact that European countries shared a common policy whose objective was to keep older people living at home as long as possible. For this to be successful, families needed to play a central role (Jani-le Bris, 1993; Mestheneos and Triantanfillio, 1993; Steenvoorden et al., 1993; Salvage, 1995). Until that time, few debates and even fewer political initiatives on supporting family care were in evidence, with variation in approach common.

In many northern European countries, there was no expectation that the family would care for dependent older people because it was assumed to be a responsibility of the state (Jani-le Bris, 1993). This dependence protection model essentially provided social services, and to a lesser extent economic incentives and support for caregiving. However, increasing costs ultimately led to either hiring private social services or rising reliance on family care.

By contrast, southern countries, such as Spain, did not even contemplate the idea that anyone other than the family would provide care, and thus the state intervened only in cases of extreme economic hardship (Jani-le Bris, 1993). This Mediterranean model, as it is known, aimed support primarily at citizens lacking resources.

Other countries, such as the Netherlands and the UK, already had specific policies aimed at family care, although they were fragmented and limited in scope (Jani-le Bris, 1993).

Today, strategies and programmes to support family care are being developed and implemented –some for the first time- in several European countries, and those that already have experience of them, such as the UK, need to rethink their approach (Nolan et al., 2008). Most of the initiatives aimed at supporting family care focus on the instrumental dimension of care and are primarily motivated by economic and pragmatic purposes (Ward-Griffin and McKeever, 2000).

A major European Commission background report (Mestheneos and Triantafillou, 2005) examined services for families across Europe and concluded that the creation of more innovative and creative support services with partnerships between family and professionals should be a priority in Europe (Nolan et al., 2008).

Particularly in Spain, the traditional model of family care has mainly relied on the role that women play in caring for dependent people. However, it is recognized that this approach is no longer adequate (Larizgoitia, 2004), and that there is a need for a new social policy that ensures the universal protection of dependent people and their carers. In response, and with the aim of improving the quality of life for individuals reliant on care and the families who care for them, in 2006 the *Act 39/2006 'Promoting Personal Autonomy and Attention to People in Situations of Dependency'* (*LAPAD*) was adopted and came into force on 1 January 2007. This universal law has established rights for all Spanish citizens who are in a situation of dependency and cannot care for themselves. With this law the LTC system was created, formed by public authorities, national government, regional government and local corporations.

This Law stipulates assistance benefits by means of services in cash or in kind, the former having priority. The rights and benefits of this initiative have been applied gradually and according to an established schedule. Until the Act is fully implemented, supposedly by 2015, access to benefits is primarily subject to the degree and level of dependence of the affected person, and secondly according to the applicant's financial means. .

This policy initiative highlighted the importance of creating a public network of care for dependent people as well as the political and institutional will to support this sector of the population. However, its implementation has not been easy (Duran, 2013). Firstly, the concept of dependence adopted by this law includes a wide variety of people, with different needs and profiles, who require different responses. The needs of a child with Down syndrome cannot be compared with those of an older person with AD; experts in the field suggest a review of the concept and the (potential) recipients of this initiative. Secondly, a recent study exploring the family experience in the transition to dependence of an older relative (Canga, 2011) confirmed that the impact this has on families goes virtually unnoticed by this relatively new policy initiative, which fails to consider the family context. As this study concluded families want to continue caring for their old relatives, but with support services that complement their efforts rather than seek to replace them.

Summary

This chapter has set the scene for the remainder of the thesis by considering demographic changes and the challenges they pose, with particular focus on the situation in Spain.

Although population ageing is considered a success for modern societies, it poses important challenges, such as increasing frailty and dependence. The family has a fundamental role in providing care for dependent people. However changes in its structure and lifestyles are questioning the sustainability of such care as while there is an expected growth in demand for care of long term care the ability of the family to meet these is declining. Therefore preserving the sustainability of family model entails the development of health and social policies targeted to protect and provide support services that complement the family´s effort and work in partnership with them.

Governments around the world have made explicit their concerns about the current context by developing and implementing health and social care plans to address the needs of an ageing population and their family carers. In Spain the implementation of new legislation and a reorientation of health care provide a counterpoint to the pathologizing and curative approach that has tended to dominate the Spanish national health system. However it is too early to know if it will be successful and critics suggest that the new law has a number of fundamental flaws

Having considered the overall context the next chapter turns attention to a specific consideration of the challenges posed by AD the focus of this study.

CHAPTER 2

DEMENTIA AND ALZHEIMER’S DISEASE: AN OVERVIEW

Introduction

Worldwide dementia is considered a leading cause of disability and dependence among older people (WHO, 2012). Alzheimer´s disease (AD) represents the most common type of dementia, especially in people aged 65 and over. Although its prevalence is associated with age, it is not regarded as a normal part of ageing. This chronic and progressive condition affects different higher cortical functions such as memory, thinking, behaviour and the ability to perform everyday activities. Thus the person affected gradually requires support and care that evolve over time. Most of that care is provided by the family, the major source of support for dependent people and a crucial element to ensure the sustainability of the long term care system (WHO, 2012).

The future prevalence and incidence of dementia, as well as the extensive impact this condition may have on the individual, family and society have led national and international organizations to recognize dementia, and therefore Alzheimer’s type, a key challenge to the public health agenda worldwide (WHO, 2012; Prince et al., 2013). Countries around the world are taking part in the ‘Alzheimer’s movement’ aiming for the implementation of comprehensive care models in dementia, which consider the person with AD and the family as being at the centre of the care process, from the beginning. This chapter traces the current medical and social context of dementia and its impact on health and social policy, especially in Spain.

The chapter begins with a brief description of dementia syndrome, emphasizing the Alzheimer´s type since it is the most prevalent form of dementia and the focus of this study. Subsequently data on the current epidemiologic context of this condition is provided, followed by a discussion on the increasing importance of dementia and AD in the public health arena. A summary of the main international policy initiatives in dementia is presented, concluding with the state of art in Spain which provides a context for this study.

2.1 Dementia and AD: Conceptualization and Epidemiology

Dementia is conceptualized in different ways according to which attribute of the condition is emphasized (e.g. pathophysiologic aspects, clinical symptoms) and the approach adopted by the author (e.g. in terms of disability). However a widely accepted definition provided by the WHO in 1993 regards dementia as (ICD-10, p.46):

> *a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.*

The multicausal nature of dementia combined with the absence of biological marker for the disease, makes the diagnosis process fairly complex (Alloul et al., 1998). Even today the only certain means of confirming an accurate diagnosis and the type of dementia is through a histological examination of the brain tissue after death (Cummings et al., 1998). In practice, the identification of the condition largely depends on clinical manifestations; so potential people with dementia are assessed and diagnosed based on the patient’s health history and a broad range of screening instruments and neuropsychiatric tests.

Alzheimer’s disease is the most common form of dementia and possibly contributes to 60–70% of cases (Cummings and Cole, 2002). It is followed by other major contributors such as vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Each subtype has especial characteristics but mixed forms often co-exist. According to the American Association for Geriatric Psychiatry, AD is characterized by decline primarily in cortical aspects of cognition (e.g., memory, language, praxis) and follows a characteristic course of gradual onset and progression (Lyketsos et al., 2006).

Alzheimer's disease affects each person in a different way, depending upon factors such as pathology and the person's pre-morbid traits. However three stages are largely identified according to its clinical progress: early stage, middle and late stage (Prince et al., 2013) (Table 2.1). These periods inform treatment and caring approaches, but the way people live with AD often differs. However as people with AD become more cognitively and functionally impaired, many lose the ability to care for themselves and become reliant on others for their daily care (Feldman et al., 2005).

The ambiguous nature and various predisposing factors to this condition challenge diagnostic criteria as well. Today common standards used in clinical practice are those proposed by the *National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer´s disease and Related Disorders Association* (NINCDS-ADRDA) and the *Diagnostic and Statistical Manual of Mental Disorder (*DSM-IV). The DSM-IV criteria principally focus on the presence of memory impairment and cognitive deterioration in domains such as language, perception, or motor skills, or disturbances in executive functioning (APA, 2000). The NINCDS/ADRDA standard, instead, determines the probability of AD in terms of three categories: definite (clinical diagnosis together with a histological confirmation of AD), probable (clinical diagnosis without a histological confirmation), and possible (atypical symptoms with no apparent alternative diagnosis in the absence of a histological confirmation) (Mckhann et al., 1984). Different studies that compared these criteria (NINCDS/ADRDA and DSM-IV-TR) with other 'gold standards' concluded that the sensitivity of assessments ranges from 65% to 96% while specificity against other dementia types diagnosis ranges from 23% to 88% (Varma et al., 1999; Hogervors et al., 2000; Petrovitch et al., 2001; Hogervors et al., 2003; Dubois et al., 2007).

Table 2.1 Common stages in AD

Stage	Common Symptom
Early stage	Those affected become forgetful, show orientation difficulties (confusion about time, place and people), and have difficulties in making decisions (including managing personal finances) and in carrying out household tasks. Furthermore, mood and behaviour can be affected, with a loss of motivation and interest, symptoms of depression, or uncharacteristically angry reactions. Caregivers have then to provide emotional support, to remind the person about events and tasks and to provide assistance with instrumental activities (for example managing finances and shopping).
Middle stage	Difficulties in communication increase, and need for help with personal care often extends to personal hygiene. Older people with dementia are no longer able successfully to prepare food, cook, clean or shop – hence living alone can be challenging even with support from family or paid caregivers. Behaviour changes (including wandering, repeated questioning, and calling out, clinging, agitation and aggression) can occur, sometimes driven by psychological and organic features (delusions, hallucinations, disturbed sleep pattern). Such behaviour can be challenging and/ or unsafe at home or in the community, meaning that the person with dementia must be more or less constantly supervised. Communication strategies to aid understanding are necessary. Help with carrying out personal care and with other activities of daily living is increased (food preparation, appropriate dressing, bathing, toileting).
Late stage	The person affected can be unaware of time and place, unable to recognize relatives, friends, or familiar objects, unable to eat without help, severely restricted in their mobility, and sometimes bed-bound. Care, support and supervision needs are more or less constant. Full physical care has to be provided, while caregivers may still have to deal with behavioural problems.

Source: Prince et al. (2013) *World Alzheimer Report 2013 Journey of Caring. An analysis of long-term care for dementia.* London, ADI. p.25.

Although AD cannot be understood as an inherent consequence of the normal ageing process, it is linked to age so its incidence and prevalence increases in line with the ageing population (Bermejo, 2004; Caselli et al., 2006; Burns and Lliffe, 2009; Jicha and Carr, 2010). Its incidence increases exponentially after 65 years of age (15.1 cases per 1000 person-years) reaching 69.2 cases per 1000 people-year in people aged 90 years and over. Prevalence differs with age, and is typically estimated at 15–20% of the population over 65 years, reaching more than 50% for individuals above 85 years (Jicha and Carr, 2010). According to data provided by the WHO (2012) in 2011 about 35.6 million people suffered dementia. Future epidemiological predictions expect that this figure will nearly double every 20 years, reaching 65.7 and 115.4 million by 2030 and 2050 respectively (ADI, 2009).

Western European countries rank first with the highest number of people with dementia (7.0 million), followed by East Asia (5.5 million), South Asia (4.5 million) and North America (4.4 million). The study conducted by Wancata et al. (2003) predicts that the European figure will rise to about 12.6 million in the following five decades. With regard to Spain, dementia prevalence varied substantially across surveys in age-specific groups. A recent study conducted by de Pedro-Cuesta et al. (2009) that reanalyzed previous dementia prevalence surveys in the population (aged 70 year and above) of Central and North-Eastern of Spain, found that differences in crude prevalence for participants aged ≥ 70 years were consistent across gender and age groups, ranging from 3.5% in Bidasoa to 17.2% in Pamplona (the city where the present study was conducted). Age- and sex-adjusted prevalence in the same age-group ranged from 3.2% in Bidasoa to 12.3% in Gerona, while the corresponding figures in the El Prat survey were intermediate (9.6 and 9.3%). In the case of AD both gender, age- and sex-adjusted prevalence at age ≥ 70 years, ranged from 2.6% in ZARADEMP to 7.7% in El Prat.

Fitzpatrick et al. (2005) estimate median survival with AD is at 7.1 years and 3.9 with vascular dementia. Data obtained by Brookmeyer et al. (2002) suggested that survival after diagnosis ranged from 8.3 years in people diagnosed at 65 years old to 3.4 years in those already aged 90 at the time of diagnosis. The complex assessment of the independent contribution of dementia to mortality may contribute to this variability between mortality measures. Sometimes comorbidity related or not to dementia may contribute to people´s death making assessment more difficult. Considering the EURODEM mortality relative risk, 10% and 15% of deaths in older men and women, respectively, are attributable to dementia, mostly among people aged between 80 and 95 (Knapp and Prince, 2007).

Dementia, and AD, are not only an important cause of death but one of the most significant causes of disability and dependence among older people (IMSERSO, 2008), representing a major challenge to welfare systems due to the high levels of support that people with these conditions often require. The *Global Burden of Disease* (2003) estimated that dementia contributed 11.2% of years lived with disability, due to a non-communicable disease, in people aged 60 years and older; more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%), and all forms of cancer (2.4%) (Ferri et al., 2005). Similarly, the *Written Declaration on Priorities in the fight against Alzheimer's disease* of the European Parliament (2008) and the WHO's report *Dementia: a public health priority* (2012) recognized AD as the leading cause of disability and dependence in ageing populations, both in developed and developing countries.

As previously mentioned AD is a chronic, disabling, progressive and, at the moment, incurable condition. Hence health and social care interventions focus primarily on maintaining and improving the quality of life of those affected and their family carers. Addressing the needs of these groups has become a major focus of economic and health policy, partly motivated by the high cost of care for the state and society as a whole. Worldwide the net cost of dementia has been estimated at approximately US $604 billion. A recent review of economic studies conducted in several European countries concludes that the cost of dementia care is considerable, with an estimated average of €28,000 per patient, but with large differences between countries (Jönsson and Wimo, 2009). Regarding Spanish figures, dementia care costs range between €27,000 and €37,000 per year, of which the largest percentage corresponds to the expenditure on informal care (77-81%), while only 10-13% corresponds to health care expenditure and 6-12% to formal non-health care.

Whilst the economic costs are significant they cannot be compared with the impact this condition has on both the person and the family as a whole. The challenges that living with Alzheimer may inexorably affect the quality of life of all involved, if they are not well addressed.

2.2 Current Dementia Policy and Plans

Worldwide numerous policy strategies and frameworks have been developed to improve the quality of life of people with dementia and their families. Although most of these are based on common guidelines, initially provided by the WHO (2001), each country has adopted its own approach to the issue. Currently fourteen countries have already designed and implemented their own national plan (Table 2.2) while others such as China, Czech Republic, Belgium, Luxembourg, Cyprus, Portugal, Malta and India are on the way of developing specific strategies in ‘the fight against dementia’.

This ‘Alzheimer’s movement’ was strengthened following the Kyoto Declaration of 2004, in which the International Federation of Alzheimer Associations (ADI) provided a series of recommendations for dementia care plans targeted at country level. The following list identifies the main areas for action proposed at that time and is still relevant:

- Provide treatment in primary care
- Make appropriate treatment available
- Give care in the community
- Educate the public
- Involve communities, families and consumers
- Establish national policies, programs and legislation
- Develop human resources
- Link with other sectors
- Monitor community health
- Support more research

In Europe, an official declaration on the political priorities on AD was adopted in 2006 (Alzheimer Europe, 2006), embracing, above all, i) strategies to improve public awareness and understanding of dementia and combating stigma; ii) equal access to health, social and other community support services and iii) ethical research approaches that recognizes and protect the vulnerability of people with dementia involved.

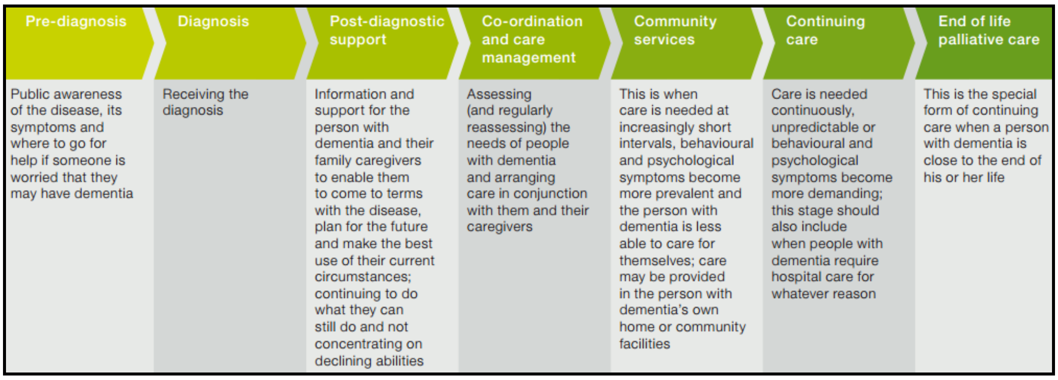
Table 2.2 Current policy on dementia by country

COUNTRY	DEMENTIA PLAN/STRATEGY SCHEDULE
Australia	The dementia initiative: Making dementia a National Health Priority (2005-2013).
Canada	Alzheimer Strategy: Preparing for our future (1999-2004).
South Korea	War on Dementia (2008-2013).
Denmark	National Dementia Action Plan (2011-2015).
Scotland	Scotland’s National Strategy (2010-2013).
United States	Subnational plans (…).
France	French Alzheimer’s Disease Plan (2008-2012).
Wales	National Dementia Vision for Wales (2011- …).
United Kingdom	Living well with dementia: A National Dementia Strategy (2009-2014).
Northern Ireland	Improving Dementia Services in Northern Ireland (2011-2015).
Japan	Emergency Project for Improvement of Medical Care and Quality of Life for People with Dementia (2008- …).
Norway	Dementia Plan 2015 (2007-2015).
Netherlands	Caring for People with Dementia (2008-2011).
Switzerland	Alzheimer’s disease and related disorders (2010-2013).

2.2.1 Health and Social Care Systems in Dementia

Ensuring the quality of life of people with dementia and their families mostly requires integration and coordination of health and social care services (WHO, 2012). This approach may contribute to a continuum care in which professionals guide and support people throughout the transitions that occur over the course of dementia. The World Alzheimer Report 2009 launched a framework for dementia care, which provided stage-care strategies that reflected the progressive nature of the condition (Figure 2.1).

Figure 2.1 Seven-stage model for planning dementia services



Pre-diagnosis	Diagnosis	Post-diagnostic support	Co-ordination and care management	Community services	Continuing care	End of life palliative care
Public awareness of the disease, its symptoms and where to go for help if someone is worried that they may have dementia	Receiving the diagnosis	Information and support for the person with dementia and their family caregivers to enable them to come to terms with the disease, plan for the future and make the best use of their current circumstances; continuing to do what they can still do and not concentrating on declining abilities	Assessing (and regularly reassessing) the needs of people with dementia and arranging care in conjunction with them and their caregivers	This is when care is needed at increasingly short intervals, behavioural and psychological symptoms become more prevalent and the person with dementia is less able to care for themselves; care may be provided in the person with dementia's own home or community facilities	Care is needed continuously, unpredictable or behavioural and psychological symptoms become more demanding; this stage should also include when people with dementia require hospital care for whatever reason	This is the special form of continuing care when a person with dementia is close to the end of his or her life

Source: World Health Organization (2012) *Dementia: a public health priority*. Geneva, WHO Press. p.53

Since this study focused on the experience of AD during early stages, it is important to consider the strategic areas for action during that period (diagnosis, post-diagnosis and community care).

The importance and value of an early diagnosis of dementia has been a consistent focus in the literature. The Alzheimer Report 2011 on early diagnosis and intervention suggested that the benefits of timely diagnosis included relief of stress due to a better understanding of symptoms, risk reduction, maximising decision making and autonomy, and receiving the diagnosis as a human right (ADI, 2011). To achieve this the report recommended that every country should have a national dementia strategy that focus on promoting early diagnosis and interventions through campaigns to increase awareness, train health care professionals and strengthen health systems.

Unfortunately, despite such efforts, dementia is still under-diagnosed worldwide and, importantly, diagnosis is usually made at a relatively late stage in the disease process (ADI, 2011). Factors such as professional knowledge gaps (Ahmad et al., 2010; Thomas, 2010), the stigma of dementia (Mac Rae, 1999;

Hamilton, 2008, Alzheimer society, 2010) and the false belief that memory problems are a normal part of ageing and nothing can be done are leading causes of this delay (Lliffe and Wilcock, 2005; Koch and Lliffe, 2010). This in turn results in delays in people affected and their families accessing effective interventions at an early stage (Clark et al., 2003; Prince et al., 2011).

Primary care professionals are considered key elements in identifying potential cases of dementia and referring them to the most appropriate specialists, who make a more accurate judgment, supported by the relevant diagnostic examinations. Following confirmation most early dementia care is provided at community level. As a result collaborative and joined work between health and social professionals is crucial to ensure comprehensive support services aimed at:

- Offering (emotional) support, advice and information as needed to the person affected and family, especially to help them in planning for the future and maintaining balance autonomy and freedom.
- Helping people with dementia to remain at home as long as possible, providing social engagement opportunities and respite care services for the family.
- Meeting the care requirements of affected people and family during later stages of dementia (WHO, 2012).

Lack of continuity and coordination in care may put the person with dementia and their family at risk, with them having to struggle to (re)contact with formal services once problems arise, which can result in increased costs to the system (Cody et al., 2002; Turner et al., 2004). In response to this, the Case Management Society of America suggests that case-management, understood as ‘a collaborative process of assessment, planning, facilitation and advocacy for options to meet an individual’s health need through communication and available resources’ (CMSA, 2010, p. 8) as a potential alternative to improve care and promote quality cost-effective outcomes (Pimouguet et al., 2010). To this end the new strategy for addressing chronicity in Spain is integrating two figures (nursing case manager and ‘transitional professional’), previously nonexistent, whose competences are focused towards the achievement and continuity of this collaborative process.

These are the core elements of the newly defined strategy to address long term conditions in Spain and have also been proposed by the Confederation of Spanish Alzheimer's Associations as the basis for a National Alzheimer's Plan. They are consistent with the World Health Report (2006), *Working Together for Health,* and the five core competencies for supporting people with long-term conditions may contribute to better outcomes in dementia care. These are:

1. **Person-centred care**, through individualized care plans, taking into account the needs, values, and preferences of people with dementia and their family.

2. **Partnering** based on collaborative and coordinated relationships between different health and social agents involved. Dementia care is not confined to a discipline, but must set up a framework for multidisciplinary relationships and synergies toward a common goal.

3. **System quality improvements** targeted at better quality of life for people with dementia and families.

4. **Information and innovative technology** to ensure continuity of care and effective communication processes among health providers and users.

5. **Community based strategies** to promote healthy lifestyles and social awareness of dementia.

A balanced Alzheimer's care model requires an holistic, interdisciplinary, multiprofessional and multisectoral approach that integrates health and social care and provides the right support and care, at the right time, to the person with AD and the family, safeguarding the interests of both sides, recognizing the value and identity of the person with AD throughout the course of the condition, and preserving the ordinary aspects of their lives. According to Weaks and Boardman (2003) *'(…) people with dementia and their family carers have the right to access care that enables them to continue to live their life as fully as possible'* (p.186). Therefore, support and care services need to be steeped in the experience of living with Alzheimer from the perspectives of both the person with AD and their families (Woods, 2001; Quinn et al., 2009).

2.3 The Alzheimer´s Care Model in Spain

In Spain the Alzheimer's care model, following the general dependence care model already described, has been based upon a traditional family care system in which family members, and especially women, have assumed the vast majority of care (Vellone et al., 2008; Losada et al., 2008). However addressing the challenges posed by this condition is no longer exclusively seen as a family matter but as an issue that affects society as a whole (Ministry of Labour and Social Affairs, 2006) and requires commitments and responsibilities from both the family and the state. In this regard the Spanish health care system and social policies are undergoing a transition aimed at promoting a partnership between the family and the state.

Spain still lacks a National Policy on Alzheimer. However the National Association of Families of People with Alzheimer's and other Dementia Types (CEAFA) is at the forefront of the movement for its implementation. In 2010 the *Spanish Alzheimer´s Alliance* was formed followed by the initiative of *Supportive Cities and Institutions with Alzheimer's 2012*, which has been currently signed by more than 250 cities and other entities in Spain. In 2013 a Task Force on Alzheimer's disease, as well as the Committee on the elaboration of the National Strategy for Neurodegenerative Diseases promoted by the Ministry of Health, Social Services and Equality of Spain were established. These two national initiatives represent a potentially major breakthrough.

However, despite the emerging political and organizational initiatives around dementia, the Spanish Plan on Alzheimer's will only have a real impact if the person and the family are considered as being at the centre of the care process, together with a unification of health and social care provision.

Summary

The rapid increase in the incidence and prevalence of Alzheimer's disease and its considerable impact on the person affected and families have turned it into an imperative of social and health policies around the world. AD is not just a family issue but a societal matter that raises questions around protection, support and funding.

Whatever system evolves the complex demands of AD will mean that family carers will be fundamental to the sustainability of any long-term care model, as well as to ensuring the quality of life, welfare and happiness of the person with AD. For this reason, social policies should work to promote convergence and collaboration between professional services and family care and not for the former to replace the latter. Consequently if families are to continue in their invaluable role support services must be tailored to the experiences of both the person with AD and the family in order to improve the quality of life of all those involved.

The present study sought to explore the family experience of living with AD. Using constructivist GT methodology the study seeks to better understand the processes that occur in the family while living the early stage of the condition. It is hoped that the study will have important implication for health and social care services, especially in this transitional process in which the implementation of a new comprehensive long term care strategy is taking place in Spain.

The following chapter turns attention to the literature review conducted prior the study commencing. It aims to highlight exiting understanding and knowledge on dementia and family care, and identify the sensitising concept and foreshadow questions that guided the study.

CHAPTER 3

FAMILY CARE AND ALZHEIMER'S DISEASE: A CONSIDERATION OF THE LITERATURE

Introduction

This chapter provides a brief overview of the literature highlighting the key role played by the family in support of people with Alzheimer's disease (AD). Its purpose is not to provide a methodological critique of existing work but rather to provide a thematic overview of prominent issues about the family experience of living with AD at the time the study commenced, in order to identify the sensitising concepts that informed the initial course of the study.

The chapter begins with a brief consideration of the role of the literature review in grounded theory (GT), the elected methodology for conducting the study. This is followed by an introduction to the main concepts used in this study: family and family care. Subsequently, an explanation of the literature review process is provided, indicating the search strategies used and how relevant sources were selected. The findings of the review are then presented. Primarily the review focuses on the family caregiving experience (from the dyadic perspective still prominent in research and practice literature), offering an overview of both the burdens and satisfactions of caring. The major factors that influence this experience, as well as the support interventions in addressing them, are also discussed. Significant gaps in the provision of support to the family in caregiving are also outlined. Attention is then turned to the adoption of a family system approach that locates the person with AD (and the primary caregiver) as a part of the family unit thus taking into account the experience as a whole. The resulting sensitising concepts and foreshadow questions that informed the constructivist GT study are introduced at the end of the chapter.

3.1 The Role of the Literature in GT

Prior to presenting and discussing an overview of the literature that informed this study the role of the literature in GT research must be considered. The stage at which existing literature should be consulted and how researchers ought to use it has been an issue widely disputed among GT scholars.

The founding premises of GT assert the inductive nature of the methodology and the 'neutral' attitude of the researcher to ensure that any theory emerges only from the data (Glaser, 1978). Therefore its founders, Glaser and Strauss (1967), supported the idea of conducting a review of the existing literature only after the analysis of the data has been performed. These authors, and particularly Glaser (1998), claimed that keeping researchers away from any prior knowledge and understanding prevents them from imposing existing preconceptions on their work, allowing theoretical assumptions to emerge naturally from the empirical data. However, as noted by Cutcliffe (2000), the notion that any researcher commences a study without some level of prior knowledge is idealistic. Likewise, Urquhart (2007) contends that *'there is no reason why a researcher cannot be self aware and be able to appreciate other theories without imposing them on the data'* (p. 351).

Subsequently a number of researchers have questioned the idea of pure induction and advised considering the literature prior to the study (Morse, 1998; Charmaz, 2006). By doing so the researcher is able to provide a well-argued rationale for the study and the chosen methodology and identify potential gaps in the existing knowledge (Coyne and Cowley, 2006; McGhee et al., 2007). In addition, early reviewing of the literature can help to contextualize the study (McCann and Clark, 2003a) and offer guidance for future research decisions, for instance, initial sampling strategies and themes to cover in the interviews. The literature may also stimulate theoretical sensitivity to noteworthy concepts or ideas that may emerge from the data (Strauss and Corbin, 1990; McCann and Clark, 2003b). Thornberg (2012) defends an early and ongoing literature review in GT studies arguing that it enriches the analytical process and stimulates researchers' questioning of their own study, by making comparisons between emergent concepts and literature. This author goes further and develops what he calls ‘informed grounded theory’: ‘*a product of a research process as well as to the research process itself, in which both the process and the product have been thoroughly grounded in data by GT methods while being informed by existing research literature and theoretical frameworks’* (p. 249). This informed approach permits the researcher to take advantage of pre-existing theories and knowledge on the field in a sensitive, inspired and flexible way. That is, these are not uncritically adopted in the study but judged in terms of their relevance and utility as a set of sensitising guidelines (Thornberg, 2012). Others, such as Charmaz (2006) argue that *‘guiding interests, sensitising concepts, and disciplinary perspectives often provide us with such a points of departure for developing, rather than limiting, our ideas’* (p.17).

From a more pragmatic viewpoint, some of the requirements that a researcher has to go through prior to commencing fieldwork, for instance, progression from Masters to Doctorate and gaining ethics approval, usually depends upon producing a detailed research proposal, rooted in a literature review.

In my case, a consideration of the literature was undertaken in the early stage of the study in order to:

- familiarize me with previous work and develop a critical understanding of central concepts related to the study;
- identify what knowledge gaps exist and justify the need to conduct the study;
- identify and produce sensitising concepts and foreshadowed questions to initially inform and guide the direction of the study.

In essence, the purpose of considering existing knowledge was to gain an understanding of current knowledge and to guide the direction of the study. In this way the sensitising concepts and foreshadowed questions identified arose from a variety of sources including the literature and my prior experiences and conceptions on the topic, together with key concepts such as the family, largely informed by the family systems approach developed by Wright and Leahey (2000).

At this point only the literature that was available at the time the study began is considered, as it was only this that could have informed the study at the outset. Significant literature and knowledge that emerged as the study developed was not considered until later and will be covered in the discussion chapter.

3.2 Framing the Study: Family and Family Care Conceptualization

Since the study focused on the family experience of living with AD, and consequently on the caring experience, it was considered appropriated to have an understanding of the overall approach to some of the relevant concepts used. Thus this section provides a brief overview of the conceptualization of family and family care that were taken into consideration in the study. These represent my broad level of awareness and the assumptions that I held **before** conducting the literature review and might therefore be considered as what could be called **foundational** sensitising concepts.

3.2.1 Defining the Family

There is still no consensus on the definition of the family but rather several conceptualizations exist, depending on the lens through which scholars view the family. Some experts in the field refer to ‘families’ rather than a single model since they accept all possible family circumstances as a model. By contrast, other authors firmly believe that there is a unique model of family (Bernal, 2005). Despite this ongoing debate there is a universal agreement in that *‘the family is the natural and fundamental group unit of society and is entitled to protection by society and the State’* (Universal Declaration of the Human Rights, 1948, Article 15, paragraph 3). This premise illustrates the central and radical nature of family life in society. It is therefore considered the basic unit of society and the social institution that has the greatest effect on its members (Friedman et al., 2003).

Burgess (1926) proposed as the most appropriate way to conceptualize and study the family considering it as a ‘*unity of interacting personalities’*. The author represented to some extent the bridge between 19th-century conceptions of the family, largely seen as a ‘*unit in social evolution’*, to the prominent 20th-century ideas of family as the supporting institution for individuals' needs. Thus, for this author the family is dynamic in essence, an interactional system influenced by its members and not merely a structure or a household. According to Bengston (2001), the behaviours of one member of the family may not be understood except in relationship to other family members, their ongoing interactions, and the personalities developing through such interactions.

Koerner and Fitzpatrick (2004) developed three general perspectives in defining the family. The first one was based on the structural features of the family: the presence or absence of certain family members who are related by blood or marriage ties. The second approach emphasized the psychosocial function of the institution in performing tasks such as housekeeping, child rearing, caregiving, and individual role fulfilment. While the third perspective focused more on the transactional concept in which the family is viewed as an intimate group of people characterized by strong ties of interdependence and commitment. In connection with this third perspective Allen et al. (2000) emphasize the socio-emotional ties and the ongoing responsibilities of the group. Harmon (2005) goes further conceptualizing it as *'two or more individuals who depend on one another for emotional, physical, and economical support. The members of the family are self-defined'* (p.7). This definition adds the significant notion of the family as a self-defined group. Similarly Friedman et al. (2003) refers to family as the members who are joined by bonds of sharing and emotional connections and who identify themselves as being part of the family, providing a more comprehensive vision of the family and encompassing a variety of relationships. This resonates with Harmon's (2005) viewpoint that the most 'certain' way of determining who the family is, is by asking the individuals.

Given that exploring the nature of the family and determining a universal model or paradigm exceeded the purpose of the study, it is important to articulate some assumptions on the approach to the family that was adopted here. The following statements, according to Wright and Leahey's work (2000), provide the essential foundation:

- ***'The family is who they say they are'*** (p.50). Therefore in the study the family was defined by its members (persons), identifying who was part of it and who would take part in the study (e.g. participants without blood ties between them).

- **The whole family unit is greater than the mere sum of its members.** The family was the unit of interest and analysis in this study, therefore the ‘whole’ experience was what counted.
- **All families have strengths that sometimes go unnoticed.**

This approach is based on the Family System Theory, which emerged from the General Systems Theory originally delineated by von Bertalanffy (1950). This theory understands the world in terms of integrated relationships, in which there are complex elements in mutual interaction (Friedman et al., 2003). The general systems approach takes into account how elements interact with each other rather than being focused on each one of them separately. Its essential principle lies on the attention to dynamic organization, this means, -the relationships between elements, concentrated in circular rather than linear relationships, and -the consideration of facts in the context in which they were given, rather than isolated from their environment.

The Family System Theory in particular considers the family as a system, which means that it is the how members come together that define the family. Therefore interest is placed primarily on the interactions and mutual dependence between its members rather than its members individually (Wright and Leahey, 2000; Bell, 2009). This notion is further developed later.

This was, therefore, the assumptions underpinning the wider notion of the family that I took into the study. Below I make clear the assumptions about the nature of family caregiving that I took into the study.

3.2.2 What Do We Mean by Family Care?

Although the concept of family care has been extensively used within the social and health care literature its meaning is still being debated. However, the instrumental aspects of care still tend to dominate the literature and services ideologies, reducing its meaning to a set of activities that the carer ‘makes’ (Jansson et al., 2001). Several researchers have argued that family care cannot be just defined as merely the performance of tasks and practical activities (Nolan et al., 1996; Perry et al., 2004; Clark et al., 2008; De la Cuesta, 2009).

Caring is a human activity, its aim goes beyond disease. According to Colliere (2005), it is everything that helps someone to live and exist; therefore, it refers to everything that stimulates life. It might be said that caregiving is the set of all those physical, mental and emotional human activities aimed at maintain the health and welfare of the person, so that he or she may achieves a good quality of live (IMSERSO, 2005). Consequently family care is recognised a complex activity that transcends caring at home and often continues even when the person moves to live to a nursing-home (Nolan et al., 1996; Jansson et al., 2001; Wilkinson and Lynn, 2005; Schulz et al., 2004). Relatives worry about their loved ones and therefore they care for them. The moral commitment to care and the suffering of loss are two universal themes in the caregiving field which clearly reveal that ‘caring for’ goes beyond the simple development of practical tasks (De la Cuesta, 2009).

Van Manen (2002) defines caregiving as a ‘type of worry’ which implies a range of invisible and intangible elements. Schumacher et al. (2000) acknowledges additional core processes, apart from providing direct care, such as monitoring, interpreting observations, making decisions, making adjustments, getting care resources, working together and negotiating with health professionals. Similarly Sebern (2005) recognizes as critical components of family care the communication, decision making and reciprocity. This author regards family care as a ‘shared process’. This idea captures the relationship between the caregiver and the care recipient and serves to account for the negative and positive aspects of this experience. Indeed, the negative effects that care may have on the family have been widely documented, especially in the field of dementia. However, it also entails positive aspects that come from the gratification of caring for someone (Grant and Nolan, 1993; Nolan et al., 1996; Grant et al., 1998). The caring experience is also now widely recognised as a temporal experience that may both start and end unpredictably (Nolan et al., 2008). Therefore when strategies to support caregivers are developed and implemented, they should be considered within this broader view of family care (De la Cuesta, 2009).

In the case of caring for someone with dementia, this often develops slowly and evolves gradually over time; therefore (in most cases) dementia family care is not a short-term, nor a clear cut, commitment but a changing and dynamic experience (Aneshensel et al., 1995; Keady and Nolan, 1994; Keady, 1999). As such it comprises numerous and variable dimensions ranging from simple tasks to much more complex and sophisticated activities/strategies. However, it is once again ‘hands on’ care that has tended to dominate the way the caregiving experience has been conceptualized in the context of dementia. While not underestimating the importance of such care, concerns about this restrictive definition and its prevalence in support services for dementia family caregiving led Bowers (1987) to explore further the meanings and purposes of care as defined by person who provided it. She conducted a study with female children caring for their older parents suffering from dementia, concluding with the identification of five different types of care which differed in purpose and that evolved over time:

- *Anticipatory care* based on the idea of anticipating future need, with the key-notion of being 'just in case'.
- *Preventive care* which implies ‘monitoring at a distance’.

The author argues that these two types of care listed above are deliberately kept from the person concerned and once this cannot be sustained in time, the care scheme changes toward more direct care, such as:

- *Supervisory care* in which there is a closer monitoring of which the cared-for person is more likely to be aware.
- *Instrumental care* referring to the practical care.

However, the motivating force behind all the above, and the most important and difficult aspect of care was defined as:

- *Protective care* being those care strategies aimed at maintaining the self-esteem of those being cared for. Later, this category was replaced by the notion of *Preservative care*, based on the need to preserve the cared-for person's sense of 'self'.

As noted above Bowers found that protective care was regarded by daughter caregivers as the most stressful and important type of care, while practical care, the type that received the greatest attention by formal services, was considered the less demanding and important.

Although this typology provided a significant step towards a more holistic concept of caring in dementia the work was developed further by Nolan et al. (1996) who presented a revised typology of family care, maintaining some of the above categories, although with slight nuances, and adding two new types (*re)constructive care* and *reciprocal care*. While *preventive*, *supervisory* and *instrumental* care types remained largely the same, *anticipatory* care, *protective* and *preventive* care changed in meaning, as follows:

- Nolan et al. argued that *anticipatory care* could extend throughout the caregiving history, changing in nature and form over time (from anticipated possible events to anticipated likely events).
- They argued that although *protective care* is motivated by high ideals, it is a care strategy of relatively limited duration and value.
- *Preservative care* also occurs throughout the various stages of the caregiving history and extends beyond preserving dignity and self-esteem to include the preservation of skills, abilities and interests of the affected person.
- The new category, *(re)constructive care*, aims at building upon the past in order to develop new and valued roles for both the cared-for-person and the family carer.
- Finally, *reciprocal care* is recognized as the core category that acknowledges the mutual and reciprocal elements in a caregiving relationship.

In their work, Nolan et al. (1996) also recognize a temporal relationship between *protective*, *preservative* and *reconstructive care* hopefully providing a better understanding of how caregiving changes over time and thus emphasizing the dynamic nature of this experience.

Building on this notion of temporality and dynamism and inspired by the work of Wilson (1989), Keady and Nolan (1994) and subsequently Keady (1999), who integrated both the carer and the person with dementia perspectives, developed a temporal model that demonstrated the changing nature of the dementia experience but also provided insight on the proactive strategies adopted by both the person and the family carers. The six stage model that they developed recognised the importance of prior relationships in shaping the context of care and argued that during caring parties may ‘work’ either together, separately or apart which helps to determine the nature of the caring experience.

What was also clear from the literature is that whilst each situation is unique, ‘threads of continuity’ may be indentified (Aneshensel et al., 1995; Keady and Nolan; 1994; Nolan et al., 1996; Keady, 1999). These broad stages may help to predict the occurrence of certain types of demands at varying times in the dementia caring journey. Therefore, they can provide as indicators of the type of support that is more appropriate at a given point in time (Nolan et al., 2008). As Aneshensel et al. (1995) already suggested:

> *‘The form, content and timing of interventions should depend to a considerable extent on where carers are in their careers, and involve an understanding of what has passed before, and what is likely to be ahead. That is, the problem encountered today should be viewed against the backdrop of yesterday and with an eye towards tomorrow’* (p.306).

Building on the above the following assumptions regarding family care, specifically in dementia, were taken forward to the study:

- **Family care is far more than the performance of tasks.** It is complex and thus the study was interested in the range of ‘experiences’ within the family.
- **The family caring experience is temporal and dynamic** and this contributed to the decision to choose grounded theory as the methodology for the study (see next chapter)**.**

Having outlined the assumptions that initially informed the study attention is turned to the role of the literature.

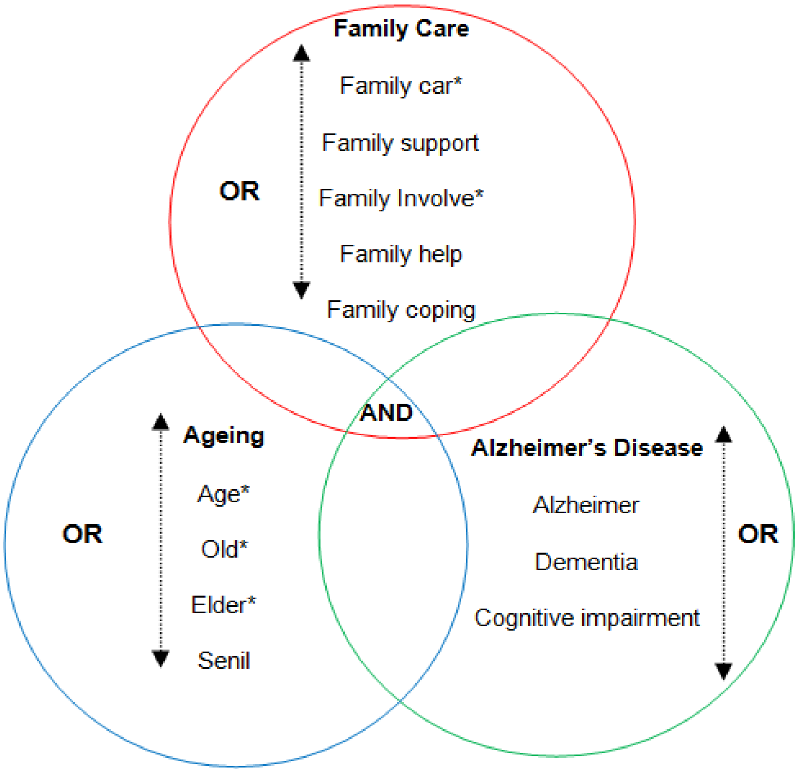
3.3 Literature Search Strategy

A narrative approach was adopted to consider the exiting literature. The intention was neither to undertake a systematic review nor to provide a methodological critique of existing studies. Rather it was to identify any existing major concepts and ideas that might add to those already identified above and thus provide some direction for the initial study.

The literature search was conducted using online electronic databases for English and Spanish-language articles from 1995 to 2010. Seminal and influential works out of this date range were also included. Most of which have already been acknowledged as informing the study (e.g. Bowers, 1987; Nolan et al., 1990; Grant and Nolan, 1993; Keady and Nolan, 1994; Nolan et al., 1994) for significant contributions to the body of knowledge of dementia family care and even for constituting a started point for many later works. The databases searched were CINAHL, PUBMED, COCHRANE Library, PsycINFO, and CUIDEN for Spanish literature. These were selected as they covered a variety of disciplines including medicine, nursing, psychology and the social sciences.

The key words used for were ‘family care’, ‘ageing’ and ‘Alzheimer's disease’ as well as their synonyms which elicited further information (Figure 3.1). These were adapted according to the requirements of each database. This review considered references which explored the family experience of living with AD, in particular, in the context of caring for older people with this condition. Boolean operators (‘OR’ and ‘AND’) were used to combine the key concepts, and terms such as ‘care’ (car*), was adopted to expand the search to all references containing that root (e.g. care, caring, caregiver, caregiving).

Figure 3.1 Search terms



The predefined inclusion criteria of the articles were the following:

- Articles focused on family care, and no other type of care such as professional/paid care.
- The family care process was provided at home
- Although AD was the defining diagnosis, studies involving people with dementia in general were also included.
- Both qualitative and quantitative approaches were eligible for inclusion in order to explore a variety of experiences that families had while caring for the person with AD.

The initial search resulted in a vast amount of potentially relevant articles, in excess of 3800 hits. In order to determine their eligibility for inclusion, a title and in some cases abstract assessment was carried out, excluding those articles that referred to other conditions, treatment, genetic and diagnosis as well as those that took place in different settings (for instance nursing homes). The number of articles reduced considerably to 173, having verified possible duplication of items between different databases. A first read of the articles collected was undertaken to get a sense of what they were about. This enabled me to decide if these were worth further reading or inclusion. For those papers that were deemed to be relevant and fulfilled the above inclusion criteria the full text was studied in more detail. Once this initial overview was completed I undertook a more systematic review of articles, eventually including 37 papers.

Although, as noted, it was not my intention to undertake a detailed methodological critique certain questions were asked of each publication including with the title of the article, the author, the purpose and methodology applied and the findings and conclusions. The use of differing checklists, depending on the type of the study (qualitative studies, quantitative studies and reviews), from the critical appraisal skill programme (CASP) facilitated the critical reading of the included items. During the process I also produced a summary of each article and included comments and thoughts that later assisted me in the content analysis and synthesis.

In addition to the electronic databases, a manual search was conducted through key journals in health and social care (Dementia, Journal of Family Nursing, and Journal of Gerontological Nursing). Likewise, web based online sources such as Google Scholar browser (and the Spanish equivalent), Index to Theses and Directory of Open Access Journals provided relevant narratives of experiences and related books and publication references from the grey circuit. The Hartford Institute for Geriatric Nursing as well as several websites on Alzheimer´s initiatives were also consulted obtaining relevant references. Beyond this, snowball strategy was used to expand the scope of the search since some identified citations referred to other potentially useful references that were not directly obtained through the above resources. These added a further 16 items which were subjected to the same critical reading and analysis process described above. Thus a total of 53 items were included in the final review.

A thematic synthesis was carried out by comparing and grouping the findings and characteristics of the items included, resulting in the emergence of three major themes, which will be further addressed in the following sections:

- The need for a balanced picture of family caregiving in the context of AD (dementia), including both positive and negative dimensions and the factors that contribute to each.
- Support strategies for family caregiving in dementia as it unfolds over time and existing gaps in provision.
- The predominance of a dyadic approach towards the experience of dementia in research and practice, and the emergence of a family systems model that considers the person with AD as a part of the family unit.

3.4 A Balanced Picture of Family Caregiving in AD

As highlighted in the previous chapter the family is the mainstay of support for the person with AD and has to deal with increasingly challenging issues over time (Ferrer and Cinebal, 2008; Weyl, 2009; DN, 2010). Caring for relatives with AD results in a series of complex changes that depend on many factors such as the family structure and relationships, the disease progression, the other demands the family may face, the financial status of the family, the availability of social resources and caregiver health amongst others (Andrén and Elmståhl, 2006; Vellone et al., 2008).

Nevertheless family care is not all about stress, burden and coping. It often also includes a positive dimension relating to human commitment, personal growth, care, affection and fidelity (Cohen et al., 2002; Keady and Harris, 2009; Netto et al., 2009). Positive and negative feelings may occur simultaneously throughout the care process. For instance, while under some circumstances people may perceive their new situation and the caregiving role as stressful, at other times they can develop an optimistic, constructive and meaningful attitude that motivates and encourages them to continue caring for their loved ones (Butcher et al., 2001; Norman et al., 2004; Sanders, 2005; Yamashita and Amagai, 2008).

Unfortunately, the negative aspects of the caregiving experience have tended to dominate the research and practice literatures leading to an understanding that rarely fully captures the complexity and reciprocity of the caring dynamic (Nolan et al., 1996; Cohen et al., 2002). Support and interventions therefore focus primarily on deficits, problems and stress that exist in families caring for someone with dementia, rather than also recognising and seeking to build on the resources and capabilities they have (Nolan et al., 1996; Cohen et al., 2002). While family caregivers require guidance and support on care strategies, disease management and adapting to progressive changes, they also need to be heard, understood and appreciated for their efforts, talents and accomplishments

Below the principal factors that according to the literature contribute to both the ‘burdens’ and ‘satisfactions’ of care, are discussed.

Factors Influencing the Experience

Health problems, psychological and emotional pathologies such as depression, anxiety and stress, as well as reduced life satisfaction are some of the risks faced by family carers who deal with the uncertainty and multiple demands of caring for someone with dementia (McConaghy and Caltabiano, 2005; Sanders, 2005; Andrén and Elmståhl, 2008; Ferrara et al., 2008). Family care in AD is mostly associated with a high risk of burnout and morbidity, and some factors (not merely the AD symptomatology) such as gender, age, timing, relationship between carer and cared for person, the resources and services available, and the understanding of the caregiver role have been identified as triggers for carer burnout. Conversely, the above studies also suggest that factors such as social support, fruitful relationships, good communication, routines and rituals, spirituality and the meaning given to the caring experience promote the satisfactions many family carers experience.

According to Nolan et al. (1996), the satisfactions of caring can be closely related to the interpersonal relationship between the carer and the person with AD, the caregiver’s personality and the wish to promote wellness in the care recipient.

Clearly relationships are a key factor in both the burdens and satisfaction of caring. Furthermore it is the balance between satisfactions and difficulties that is the most important factor (Grant and Nolan, 1993).

Nolan et al. (1990) argued that relationships have a more powerful effect on the level of stress perceived by the caregiver than the demands of care, for instance the amount of practical care provided. A close relationship between the caregiver and the person with dementia may result in high levels of burnout since emotional closeness implies a greater involvement in care (Andrén and Elmståhl, 2005). On the other hand, mutual affection, companionship and loyalty are aspects that play an important role in maintaining a positive relationship between both the person with dementia and the family caregiver, which in turn impacts on the meaning that they may have about the experience (Quinn et al., 2009). Hellström et al. (2005, 2007) in their study on the strategies that couples adopt to live positively with dementia highlight the efforts that both parties make to maintain a positive relationship by finding ways of *'being in a loving and trusting relationship'* and keeping the affection and appreciation of each other. However, not all couples are successful and as stated by Fitzpatrick and Vacha-Haase (2010), high levels of perceived burden may lead to a negative impact on marital satisfaction. The potential erosion of interpersonal ties may reduce the caregiver's feeling of effectiveness in their role as a carer, resulting in emotional distance from their love one. Relationships, therefore, seem to be central to understanding the experience of living with dementia, as this can be precursor of both negative and positive impacts on the person and the caregiver. This reinforces the idea of the dynamic nature of the relationship between the caregiver and the cared-for person.

Searson et al. (2008) in their study on activities that were enjoyed by the person with AD and the family caregiver, and the relationship between these activities and carer morbidity found that spending time together and doing activities that were enjoyable for both parties, such as sharing memories, looking at photos and going out could also help them to find meaning in their situation and thus reduce carer burden. Additionally, the relationships and connections that the person with dementia and the caregiver maintain with other close family members and friends may also facilitate a positive sense of the experience and therefore increase the satisfaction of caring (Searson et al., 2008).

Similar to the role of relationships, the way in which relatives assume the role of caregiver and the meaning they give to this experience can affect their future health status. Some family caregivers see this situation as something natural and normal within the family unit, while others may experience it as something imposed on them (Yamashita and Amagai, 2008; Quinn et al., 2009). Those caregivers that see it as a natural rather than an imposed role and adopt positive approaches to problem solving and care management are likely to experience lower levels of burnout and higher levels of wellbeing (McConaghy and Caltabiano, 2005; Papastavrou et al., 2007; Quinn et al., 2009). Adopting a flexible attitude, maintaining positive self-esteem, having the capacity to adapt and the ability to use resources rationally are qualities that help carers to overcome difficult life situations, to confront crises successfully and to adapt to the future better (Ross et al., 2003). Finding meaning entails making sense and giving order and coherence to the experience.

According to Antonovsky (1987) the way in which people interpret an event is crucial to develop satisfactory coping strategies (cited in Andrén and Elmståhl, 2008; p. 791). Thus, the understanding that family caregivers have about the disease and the new demands it creates will affect the way in which they will manage it. Antonovsky suggested that developing a ‘sense of coherence’ determines how successfully people cope with stressful situations and recognized three major components: i) ‘understanding’ which refers to the perception that the person has about the stressor and the information they collect and use to structure and clarify their situation; ii) ‘management’ referring to the resources available to the person and iii) ‘motivation’ of the person to cope with the situation. Accordingly, the ability and willingness that someone has to care for a person with AD is significantly influenced by their ability to find meaning and gratification in the caregiver role (Andrén and Elmståhl, 2005). Furthermore, a caregiver’s ability to find meaning in the care experience can potentially impact on whether they are or are not able to identify positive aspects of caregiving, which in turn may mitigate the impact of caregiving stressors and burden experience (Quinn et al., 2009).

Age and gender have been studied with regard to the level of burden experienced by caregivers, although not all studies reach the same conclusions. While authors such as Annerstedt et al. (2000), in their research on burden and the decision to place the person with AD in a care home did not identify a correlation between gender and levels of burnout, others studies conclude that women are more likely to suffer from social restrictions due to higher emotional involvement and differing ways of coping (Gallicchio et al., 2002; Papastavrou et al., 2007). Regarding age, Andrén and Elmståhl (2006) indicate that older caregivers are likely to experience higher levels of burnout than young caregivers while McConaghy and Caltabiano (2005) found no difference between perceived life satisfaction among adults and younger.

Caring for someone with AD is usually a long-term commitment and the general conclusion in the literature is that caring becomes less stressful over time: '*Caring for a person with dementia in an extended period of time is associated with a decrease in the levels of burden'* (McConaghy and Caltabiano, 2005, p. 89) since it may lead the caregiver to gain experience and develop skills to handle their situation. Moreover, caregivers may develop a sense of mastery and self-improvement in terms of handling issues that at first seemed impossible (Sanders, 2005). Nevertheless, despite such extensive experience and the potential for caring to be less stressful, the rate at which carers place their relative into alternative care increases over time, again suggesting that the situation is a complex one. The availability of help and support for AD care, either from friends, close family members or professionals are also influential, the more support and the more relevant it is the lower the level of burden, especially if it allows caregivers to take a break, have time to themselves and not feel alone (Brown et al., 2007). Moreover, good and stable financial resources are related to lower levels of burnout among carers (Papastavrou et al., 2007). This may be because those caregivers with high financial resources and good jobs can more easily access resources and support services such as informal home care and day care centres (Andrén and Elmståhl, 2006).

Clearly there is a range of potential issues that have a bearing on the experience of living with AD within the family and this poses challenges for the provision of appropriate support interventions.

3.5 Support Intervention in AD Family Caregiving as It Unfolds Over Time

Being proactive in supporting family caregivers and planning interventions in advance is likely to result in more appropriate and effective interventions for both the person with AD and their carers, thus potentially preventing the onset of problems and stressful situations within the family. These need to be related to the caring experience and how it unfolds over time.

For example, Butchers et al.'s (2001) study on the experience of caring for someone with AD, suggests that the most difficult situations involve i) dealing with stress, disappointment and the never-ending day to day care; ii) managing difficult symptoms; iii) protecting the care recipient from harm; and iv) dealing with the repetition due to memory loss. On a more practical level Yamashita and Amagai (2008) found that family caregivers identified wandering, incontinence and abusive language in AD as the most difficult problems to handle. Therefore providing a safe and secure environment is often a major consideration (Latch and Chang, 2007). However, much will depend on the way that each situation is perceived and how it develops over time.

AD is a condition that tends to 'creep on' over time and family members either do not notice the development of AD for some time or else do not perceive that their loved one has a problem (Keady and Nolan, 1994; Keady, 1999; Nolan et al., 2003). Furthermore people with dementia may not necessarily tell their relatives about the difficulties they are experiencing (Keady and Nolan, 1994; Keady, 1999; Steeman et al., 2006). However, due to the progressive nature of the condition there comes a time when it is not possible to further *'discount and normalize'* the situation and professional support is sought (Keady 1996, 1999). At this point it is important to provide families with a good understanding about the likely stages and course of the disease, possible changes and their recognition, and support the family and the person with AD to share what is actually happening (Keady, 1996; Keady and Giligard, 1999; Steeman et al., 2006).

There is no doubt that the onset of dementia and its diagnosis represents a difficult and stressful experience to both the person and the family, however it may became a challenge rather a threat if well designed and thought support is received on time (Steeman et al., 2006). Furthermore, appropriate support may help families to integrate the condition into their life and live with it more positively (Steeman et al., 2006). These authors identify the experience of uncertainty, the importance of autonomy, meaningfulness, and security, and the struggle between self-protection and self-adjustment as significant factors in shaping the early experience of the person with dementia. Similarly they argue that the relatives and the person need to adjust to each other to cope together with the changing circumstances, justifying the involvement of both, and not just one side (generally the caregiver), as active participants in their care.

In the early stages of dementia the following challenges have been identified: difficulties in getting a timely diagnosis, partial information on the diagnosis, its treatment and the available support services, and appropriate involvement in making future decision regarding care (Conell et al., 2004). Adopting a partnership approach by developing a formal, dynamic and therapeutic relationship between the family, the person with dementia and professionals may result in the reduction, or even avoidance of such challenges and promote the quality of care and quality of life of people with dementia and their families (Nolan et al., 2003).

In addition focussing on the gains or positive aspects of the family caregiving experience can bring new insights to enhance the quality of care provided as well as the wellbeing of both family and the loved one (Kramer, 1997). Thus, satisfactions of care can be a useful tool to i) enhance the positive aspects of the caregiver’s role, find meaning in what they are doing and maximize its beneficial effect through facilitating coping, promoting positive family growth; ii) evaluating the effects of the interventions directed to the family caregiver and the person with dementia and detecting those family members who are at risk of a burden experience (Grant and Nolan, 1993).

With regarding to providing resources and support services, Brown et al. (2007) highlight the need to understand when and how caregivers ask for help. Sometimes the problem is not the fact that services and support do not exist but that carers are either reluctant to ask for them or do not know they are available.

It is clear that the caregiver's values, attitudes and experiences influence their decisions about how and when they seek help and support. There may also be gender differences for example male caregivers seem to prefer the use of professional services rather than requesting assistance from other family members, friends, neighbours or other informal services (Neufeld and Harrison, 1995; Brown et al., 2007).

Numerous support programs and interventions aimed at family carers of people with dementia have been developed, although they often have different origins, objectives and strategies. Psycho-educational programmes (Kuzu et al., 2005; Hepburn et al., 2007; Losada et al., 2008), interventions focused on emotional support and burnout prevention (Stoltz et al., 2004; Farran et al., 2007; Andrén and Elmståhl, 2008) practical assistance (Farran et al., 2004; Phinney, 2006) and multicomponent interventions (Newcomer et al., 1999; Eloniemi-Sulkava et al., 2009) among others are highlighted in the literature. The aim and purpose of each intervention and the extent to which they address the real experience of the families are crucial in determining their success. Thus, proper assessment and critical appraisal of interventions is the key to their efficiency, effectiveness and suitability to meet the desires of caregivers and the person with AD (Losada et al., 2008). Gaining knowledge about the experience of living with AD, including both positives and negatives aspects, is important if professionals want to gain a complete picture of the situation, and this requires the active involvement of the whole family, including the person with AD (Ostwald et al., 2003; Pinquart and Sörensen, 2006).

The principal limitations of existing support strategies for family caregivers are presented below:

Major Gaps in Existing Support Interventions

Support initiatives for caregivers have been principally informed by a stress-burden model, failing to capture the dynamic nature of family care (Nolan et al., 1996). In daily practice orientation towards deficits, problems and the needs of families living with dementia are still a priority, rather than strengthening resources and abilities (Nolan et al., 1996; Cohen et al., 2002). As stated by

Skerret (2010) the limited vision of caring as the performance of practical tasks rather than a complex and dynamic process might contribute to the acceptance of this partial approach. This limited perspective may lead to the erroneous assumption that family carers do not have the capacity to cope with problems or accomplish their own goals without professional help, which, in turn, acknowledges the latter as the experts with solutions and resources that family lacks. This notion could explain why caregivers often stay away from professional support. Effective support interventions should, therefore, be based on an integration of the knowledge that families have about their situation and their own family, and the expertise that professionals bring. This partnership approach may help to individualize the support provided and help the family to function more effectively (Nolan et al., 2003). As noted in the earlier chapter this notion of partnership working forms the basis of many policies aimed at supporting family carers.

Professionals working in alliance with the family and the person would facilitate the development of a meaningful dialogue that respect the perspectives and expectation of the professionals and the family, which would result in negotiating and agreeing on the role each would play in the caring journey and thus assist working together to find the most appropriate responses to preserve and enact their quality of life (Nolan et al., 2003). Agreement between family caregivers and professionals about the goals, outcomes and timing of the support strategies are likely to result in these being seen as appropriate and acceptable. However if agreement is not reached caregivers may regard support services as inappropriate, out of place and irrelevant to their needs and circumstances (Nolan et al., 2003; Levesque et al., 2010).

A ‘strength-is-best’ approach emerged as a response to the previous limited view of caregiver support. It implies focusing on what individuals and families know and can do, emphasizing their capacity to build on what they have. This perspective is consistent with the postmodern notion that seeks to exclude ‘pathologizing’ discourses that simply focus on deficits (Wright and Leahey, 2000) Duckworth et al. (2005), state that even for people who experience the heaviest ‘psychological burden’, concerns should go beyond the relief of suffering alone. People desire and deserve satisfaction and joy, and not just the alleviation of sadness and worry. Therefore professionals must direct their actions towards these goals.

In addition it is also essential to tailor support to successive stages of the care-giving journey, which often have their own specific needs (Jani-le-Bris, 1993). So far there has been much effort in maintaining the caring role of the family, but what is notably absent are interventions that prepare caregivers to begin the caregiving role or to end it (Nolan et al., 2008). Askham (1997) has proposed that interventions to support caregivers should be directed to help the family to

- take up, or decide not to take up, a caring role;
- continue in caregiving;
- and end the caregiving role.

Whilst the research highlights the importance of support responding to the temporal needs of caregivers as a major review of European services reports such a comprehensive approach is not reflected in the way that support services are currently being delivered (Nolan et al., 2008).

Furthermore, the majority of existing carer-support programmes and services have been aimed at either the caregiver or the person with dementia and there is still a notable absence of support services targeted at both the person and the family, that is, focused on the whole family unit (Nolan et al., 2003; Nolan et al., 2008).

There is now growing recognition that caring for a person with AD is not separate from family life, but integrated into it and therefore AD potentially affects everyone (De la Cuesta and Sandelowski, 2005). As a consequence, comprehensive services should meet the needs of the entire family including emotional support, counselling and educational programs. To do so means viewing the person with AD as a part of the family unit. Ostwald et al. (2003) advocated a family-centred approach to dementia care and developed a support programme not only for the primary caregiver but also involving at least one other members of the family. This educational programme combined information and training for behaviour management focused on family cohesion and helping the family to find help and support in their role. Although the purpose and design of the project was rather limited (mainly focused on management and practical issues), helping caregivers, the person with AD and other family members to understand the condition process and the families' new situation helped to change their approach to living with AD and altered the family dynamics for the better (Ostwald et al., 2003). This suggests the potential benefits of adapting a more family oriented approach to both understanding and supporting family caregivers.

3.6 Advocating a Family System Approach in Family Care in AD

There has been an extensive history of research on family dementia care and support intervention. However, it has largely focused either upon the individual experience of the affected person and the primary caregiver, looking at the emotional relationship between them, as well as the coping and stress process of the latter, although, as noted, there has been an increasing emphasis on the positive dimension of caregiving. More recently there has been the emergence of a more dyadic approach that looks at the needs and experiences of both parties (Nolan et al., 2008). A family system approach has rarely been adopted (Keady and Harris, 2009), and much research has considered the person with dementia as mainly being in isolation from the family unit, ignoring the obvious fact that the condition affects and implies changes for the whole family system. As a consequence there is currently very limited research considering how AD affects the whole family and how families respond to that situation (Algado et al., 1997; Peisah, 2006; Keady and Harris, 2009).

Some time ago Algado et al. (1997) argued that AD not only has consequences for the person and the caregiver but for the whole family. Family members are mutually influenced by and mutually dependent upon one another. Indeed, bonds among members are so tight that changes (such the onset of a disease) in one of its members, or the way a member acts, may affect the others, and consequently the whole group (Herrera, 1997). Living with AD constitutes a vital transition for the whole group. It entails a new situation that interrupts the logic of the family life course and may destabilize the dynamics and normal functioning of the whole

(De la Cuesta and Sandelowski, 2005; Peisah, 2006; Keady and Harris, 2009). Friedman et al. (2003) argue that the family is constantly changing. Its dynamic nature allows it to meet the challenges associated with everyday life while attempting to maintain stability for its members and environment. Thus the family develops in an ongoing tension between trying to maintaining stability and introducing changes. Where this cannot be achieved often precipitates the onset of a crisis (Friedman et al., 2003).

Adopting a family systems approach to studying AD may provide a lens to better understand the dynamics that occur within the family at the onset of AD, how they alter ways of working and how they develop as a family from that time forward. This approach serves to highlight the interrelations and interdependencies of the family members involved in the AD experience and to understand the ways in which alterations impact on the whole family (Friedman et al., 2003; Wright and Leahey, 2000).

Adopting a family system approach is likely to result in a better understanding of the nature of the changing family dynamics over time and may help to develop support intervention that anticipate certain ‘systematic’ events that occur in the course of the AD process. This ‘omission’ of a family system approach in family care support services and research suggests that an understanding of the shared, lived experience of those involved in living with AD is required if current knowledge and evidence is to be expanded.

3.7 Literature Review Summary and Conclusion

As the literature review highlighted most previous research in AD family care has focused primarily on individual experiences, and more recently dyadic relationships, exploring mainly burden and stress although there has been a growing literature on the positive aspects of caring. However, there are still large gaps in our understanding of the entire family experience of living with AD, the role that all family members adopt, the effect that the condition has on them, as well as what they perceive as their main family goals, strengths, needs and concerns.

Considering the impact of AD on the family unit, including the person with AD, may help to better understand the meanings that the family attributes to living with AD, the relationships established between them, and recognize those aspects that prevent negative consequences and those that promote positive feelings and help to maintain family life.

3.8 Sensitising Concepts and Foreshadow Questions Guiding the Study

According to the approach advocated by Charmaz (2006), and adopted in the study, sensitising concepts derived from a literature review and the prior experiences and assumptions of the researcher constitute the start point of the study and help to frame the foreshadowed questions that are to be explored.

One of the primary assumptions brought into this study, reinforced by recent calls in the literature, is that living with AD is best seen as a family experience. Thus viewing the person with AD as a part of the family may help professionals to better understand the experience and to provide more appropriate support. The concept of a family system approach contains theoretical ideas that help to set the context and direction for this study (Wright and Leahey, 2000):

- Viewing the family as a unit and not just as the sum of its members. The assumption is made that ‘the family is who they say they are’.

- Concentrating on both the person with AD and the family simultaneously.

- Understanding the interaction and reciprocity that occurs between family members during the AD experience as well as between the family and the condition itself.

Family members are elements of the whole system that interact and establish relations between each other thereby creating the structure and dynamics of the family. These patterns of interaction are established among family members over time, however they can be disrupted by events such the onset of AD meaning that existing structures and ways of working need to be reoriented to the new situation (Wright and Leahey, 2000).

Another assumption underpinning this study is that the changing and dynamic nature of the AD caring experience has to be acknowledged. Caring is more than the performance of practical activities and tasks; it involves different dimensions and includes a variety of strategies, that involve both the person with AD and the family working (together), which often commences even before the medical diagnosis is received and evolves over time. Despite the notion that each care situation is unique and the caring experience is not uniform, potential stages may be indentified (Aneshensel et al., 1995; Keady and Nolan, 1994; Nolan et al., 1996; Keady, 1999), and these may help to predict the occurrence of certain types of family demands at varying times and ensure that the most appropriate type of support is provided at a given point in time (Nolan et al., 2008).

From these sensitising concepts the following foreshadowed questions emerge:

1. How do families, including the person with AD, experience the impact of Alzheimer's disease among of its members?

2. What does the experience mean to the person with AD and the family?

3. How does this perception influence the ways in which the family works in the context of AD?

4. How do history and family circumstances influence the experience of illness?

Therefore, the principal aims of the study are:

i) to explore the family care processes involved when an older person with Alzheimer´s disease is cared for at home and how this affects the unit, the structure and dynamics of the family.

ii) to understand what living with AD means to the person with AD and the whole family cluster.

iii) to consider the needs of the whole family, noting which resources, strengths and family strategies are used while living with AD, and understand how they want them be met.

iv) to develop a substantive theory that explains the family-care processes involved and to consider how this theory might inform the development of better support services.

Whilst in an ideal scenario, and with sufficient resources of time and finances, I would have loved to have conducted a longitudinal study exploring the above issues along the whole AD experience a decision was made to focus the current study on families living AD in the early stages.

The next chapter explores the methods that were adopted to address the above issues.

CHAPTER 4

METHODOLOGY

Introduction

As noted in the previous chapter the overall aim of this study was to develop a theoretical understanding of the family processes involved in living with early stage Alzheimer’s disease (AD) of an older relative. Thus, based on a previous consideration of the literature, the study sought to address the following foreshadow questions:

1. How do families, including the person with AD, experience the impact of Alzheimer's disease among of its members?
2. What does the experience mean to the person with AD and the family?
3. How does this perception influence the ways in which the family works in the context of AD?
4. How do history and family circumstances influence the experience of illness?

Although previous knowledge and ideas did not dictate the direction of the study a number of sensitising concepts and assumptions constituted a broad starting point. They also served to support ideas for initial coding and developing first notions about processes in data (see later for full account).

As will be argued below I chose to adopt a constructivist grounded theory approach to address the above questions. I decided to follow this approach since my aspirations for the study were directed not only to contribute to knowledge about the family's experience of living with AD but to also produce insights that may help other families to live with this condition in the most positive way possible. Moreover it was my hope that the findings of the study could inform policy and practice, and suggest improvements to support and care services for such families.

This chapter explains how the principles and methodological procedures of the selected approach were applied. It begins by outlining the rationale for choosing a qualitative method, in particular grounded theory (GT), and particularly constructivist GT. Subsequently the principal canons of this methodology are outlined. Then attention turns to the study development and the research process. The ethical aspects of the study and the criteria to be used in assessing the quality and rigour of the research work are also addressed.

4.1 Qualitative vs. Quantitative Research Paradigms

Broadly speaking scientific research may be divided into two main approaches, derived from different scientific traditions and with differing underlying assumptions: the **qualitative** approach, is more exploratory in nature and assumes a subjective stance, the **quantitative** approach asserts a position of control and objectivity (Parahoo, 1997; Gerrish and Lacey, 2008).

An intense and ongoing debate between the two exists. It is fundamentally based on the different perspectives that both paradigms hold regarding the nature of reality (ontology), its understanding (epistemology) and how it is accessed (methodology) (Guba and Lincoln, 2005). The positivist tradition of quantitative research relies on the natural sciences. Research methods under this paradigm assume that the world is stable and predictable, and phenomena can be measured empirically. This approach is profoundly connected to the traditional view of science and the use of value-neutrality as a criterion of objectivity (Gerrish and Lacey, 2008). Therefore, knowledge is based on empirical facts, paying little attention to the subjectivity of individuals. By contrast the tradition of qualitative research emerged from the social sciences and the research methods it adopts are interpretative, emphasizing the meaning and understanding of human behaviour and actions (Topping, 2008). Qualitative research provides a methodological process to understand '*the world of lived experience from the* *point of view of those who live it'* (Schwandt, 1994, p. 118). Hence it does not focus on the prediction and control of a phenomenon but in the rigorous description and understanding of peoples' everyday experience (Streubert and Carpenter, 1995). Tensions between these two research paradigms may arise if a superior posture of one method over another is assumed (Cabrero and Richart, 1996). However diversity and divergence among them do not justify superiority of either; by contrast their complementary is to generate knowledge of various kinds.

Consequently, certain research questions cannot be addressed using quantitative methods but rather require a qualitative approach that explores the subjective, holistic and dynamic aspects of human experience (Denzin and Lincoln, 2000; Gerrish and Lacey, 2008). This is the case in this study that sought to understand the family experience of living with AD in a holistic way, from the perspective of the family as a unit and the subjective experience of its primary members.

'Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between researcher and what is studied and the situational constrains that shape inquiry' (Denzin and Lincoln 2000, p.11). Thus the interaction between both the researchers and the 'researched' is an essential attribute of the knowledge production process. Qualitative research seeks to answer questions about 'what' and 'why' of a phenomenon and 'how' it is created and understood by people within their context (Green and Thorogood, 2004). For that reason researchers search for detailed information about how and why people behave, think and act in a certain way about a given experience (Ambert et al., 1995). As Taylor and Bogdan state (1998), '*qualitative researchers are concerned with the meaning that people attach to things in their lives'* (p.7). Furthermore, this paradigm accounts for the discovery or disclosure of perceptions, meanings, understanding, multiple realities and psychosocial context in social groups such as the family (Harmon et al., 2005) making it especially suitable for the purpose of the present study.

The qualitative paradigm comprises several diverse methodological approaches. For example Denzin and Lincoln (2005) recognize ethnography, phenomenology and grounded theory as the main types of qualitative studies, albeit there are a range of other approaches including case study, life history, historical method, action and applied research and clinical research. Before designing the current study consideration was given to all of these, although attention was primarily paid to the three main methodologies which hold different philosophical and methodological assumptions. For instance phenomenology, which derives from philosophy and psychology, focuses on the nature of 'being' and human experience, and deals mainly with questions that look at the essential meaning of an experience for participants (Hallet, 1995). Whereas ethnography, based on anthropology, is interested in answering questions around issues such as the beliefs, values and practices of a particular culture within a given context (LeCompte and Schensul, 1999). Neither of these two approaches seemed to attend to the central issue in the present study, which was to understand the family processes involved in living with early stage AD and how these played out over time. Grounded Theory, rooted in symbolic interactionism and sociology, seemed particularly well suited since its primary goal is to explore the social processes that underpin human interactions (Hutchinson, 1993). It aims to identify how people create, enact and change meaning and actions with regard to a phenomenon of everyday life which is produced in social interaction (Vivar et al., 2010).

Considering that AD inevitably impacts on the social processes within the family and the way in which family relationships and interactions occur, GT was thought to be particularly well suited to address the questions to be explored. Furthermore, in relation to family care, this idea was reinforced several years ago by Kahana and Young (1990) who argued for more studies that focus on the impact of the disease process on the interactions within the family and their relationship with the person receiving care. Hence GT is well-suited to conduct family studies as it offers a window into family processes through the interaction of patterns and relationships within the family.

The following section provides a more detailed explanation of why GT, and specifically, constructivist grounded theory, was the methodology adopted to conduct the study.

4.2 Why Use Constructivist GT in this Study?

Grounded Theory was originally developed by Anselm Strauss and Barney Glaser in the mid 1960s as a systematic method to generate theory about human sociology that was 'grounded' in empirical data (Walker and Myrick, 2006). Its origins fall into the Chicago School of Sociology that developed the tradition of pragmatism for understanding human systems, and symbolic interactionism in the early twentieth century. This latter movement was established as an alternative to the dominant functionalist theories in sociology and underlines the important role of symbols in human interaction. Symbolic interactionism emphasizes that people act and interact with others on the basis of the meanings that objects and people have for them (Taylor and Bogdan, 1998; Gerrish and Lacey, 2008); in other words, it is through symbols as the product of social interaction that actors interpret and give them meaning to actions. People create shared symbolic meanings through their interactions, and those meanings become their reality. This perspective acknowledges that each individual has his own background, experiences, perceptions, ideas, beliefs and values that influence the way he creates meaning and behaves towards certain events.

The influence of the above is reflected in GT through the active role that participants have in creating meaning of some situations and the attitude of the researcher trying to find out the meaning that different symbols such as non verbal-communication, clothes and acts have for people who are interacting in that moment, in order to better understand their lived experience (Cutcliffe, 2000). According to Bryant and Charmaz (2007):

> *Symbolic Interacionism and GT have strong compatibilities. Both the theoretical and the method assume an agentic actor, the significance of studying processes*[2]*, the emphasis on building useful theory from empirical observation, and the development of conditional theories that address specific realities* (p. 21).

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[2] *A process consists of unfolding temporal sequences that may have identifiable markers with clear beginning and ending and benchmarks in between. The temporal sequences are linked in a process and lead to change. These single events become linked as a part of a larger whole* (Charmaz, 2014, p.17).

Grounded theory aims to both describe and explain the phenomenon under study through data systematically gathered and analysed:

'*Essentially, grounded theory methods consist of systematic inductive guidelines for collecting and analyzing data to build middle range theoretical frameworks that explain the collected data'* (Charmaz, 2000, p.509)

That is, theory is constructed through analytical procedures and based (grounded) in data but also set in the context of a research situation. Therefore, GT does not test pre-existing hypotheses but rather aims to produce a substantive theory that identifies and explains the phenomena studied (Kennedy and Lingard, 2006). In order to achieve this goal the researcher (as well as the 'researched') formulate categories from the data that account for the variability in the data and illuminates the key 'social processes' involved.

One of the main distinguishing features of GT is its emphasis on creating and developing a particular type of theory called mid-range theory (Glaser and Strauss, 1967). This is a type of theoretical construction that has emerged from data gathered on a specific aspect of the human reality under study. Compared with 'grand' theory it has a narrow scope and use concepts that while abstract, are close enough to data to be incorporated into propositions and hypotheses that can be examined empirically (Merton, 1968). Theories of middle range are: more abstract than mere empirical generalizations, but are still circumscribed to a particular content area; elaborate more concrete concepts and relationships; focus on practical issues; and can be more easily applied by professionals in diverse contexts (Smith and Liehr, 2008). Grounded theorists through their systematic interaction with data create initial ideas and construct from prior empirical findings and transform them into 'substantive' a theory.

The goal here is to develop a substantive theory in relation to the family experience of living with early AD in the Spanish context.

Grounded theory has also evolved since its origins giving rise to different perspectives on what is understood by reality as well as its development and implementation. Initially, Glaser (1978) advocated what is now seen by some as a largely a positivistic approach to GT giving emphasis to *'logic, analytic procedures, comparative methods, and conceptual development and assumptions of an external but discernible word, unbiased observed and discovered theory'* (Charmaz, 2000, p. 509). Subsequently, Strauss and Corbin (1990) moved towards a focus on meaning, action and process based on the roots of pragmatism and symbolic interactionism, considering the GT process as a systematic reflection (positivistic procedures) of multiple perspectives. However Charmaz´s work (2000, 2006) has challenged the previous authors' efforts and she recasts GT as a social constructionist methodology that gives greater prominence to the phenomenon under study rather than the method. The central tenet of this GT scheme lies in giving voice to participants. Charmaz (2000, 2006) advocates a mutual relationship between the viewer and the viewed which results in the creation of a shared reality. Thus data and analysis are co-constructed in the interaction between both the researcher and participants, allowing a much more active role of the latter in shaping the resulting theory.

This GT variant retains the inductive, comparative, emergent and open-ended approach of Glaserian's method while embracing the iterative logic and dual emphases on action and meaning of Strauss later works', especially emphasizing the flexibility of the methods. This particular study followed the principles and assumptions of the latter approach, the Constructivist GT as this was more consistent with my desire to engage people as participants as fully as I could.

4.2.1 Constructivist Inquiry: Ontological and Epistemological Assumptions

The approach adopted in the study is based on the relativist ontology and subjective epistemology of Constructivism which recognizes i) the mutuality between the researcher and the participants and ii) the partnership approach for co-construction of reality as fundamental assumptions of the research inquiry (Charmaz, 2000). In contrast to the traditional approach of GT, constructivists advocate the involvement of the researcher but not merely as an analyst but as a co-constructor of meaning. Theory is jointly shaped by the participants and the researcher throughout the course of the study. This approach is based on the belief that knowledge is co-created by the viewer (researcher) and the viewed (participants) and attempts to understand the subjective meaning created for both participants (Charmaz, 2009). Furthermore it is the interaction between them that produces the data (Mills et al., 2006). Since my aspiration was to engage fully with participants and ponder on the role that my personal experiences and feelings would play in shaping the theory I opted for a constructivist model.

In contrast to Positivism, Constructivism assumes that reality is multiple, constructed and holistic. It is created in relationship to the view individuals have of the word and who they are in relation to it (Rodwell, 1998). According to Charmaz (2006) a *'...constructivist approach means learning how, when, and to what extent the studied experience is embedded in larger and often hidden positions, networks, situations, and relationships'* (p.130). Therefore, Constructivism brings to GT studies the opportunity to study people in their natural environment and takes it away from the traditional positivist approach (Charmaz, 2000, 2006); which means placing the research in the context and circumstance that influence on it (Charmaz, 2009).

4.3 The Defining Traits of GT

GT has been mainly used in the field of sociology and psychology, and increasingly in nursing, albeit often using different approaches. Nonetheless most grounded theorists, despite differing in their standpoints and conceptual agendas, have offered identified the 'core' properties of the methodology. Wiener, for instance, acknowledges the following as integral features of GT (Bryant and Charmaz, 2007, p.12):

- Data gathering, analysis and theory construction proceed concurrently (constant comparison);
- Coding starts with first interview and/or fieldnotes;
- Memo writing also begins with first interview and or/ fieldnotes;
- Theoretical sampling is the disciplined search for patterns and variations;
- Theoretical sorting of memos sets up the outline for writing the theory;

- Theoretical saturation is the judgement that there is no need to collect further data;
- The identification of a basis social process(es) that account for most of the observed behaviours;

Similarly Charmaz (2006) releases a summary of what really characterizes a GT study claiming that:

> *Grounded theory involves taking comparison from data and reaching up to construct abstractions and then down to tie these abstractions to data. It means learning about the specific and the general-and seeing what is new-then exploring their links to larger issues or creating larger unrecognized issues entirety. An imaginative interpretation sparks new views and leads scholars to new vistas. Grounded theory methods can provide a route to see beyond the obvious and a path to reach imaginative interpretation* (p.181).

Consequently it may be said that an inductive (abductive) logic, theoretically guided (theoretical sampling), and constant comparison aimed at creating new insights are the ‘essentials’ of this methodology. They are explained in more detail below.

4.3.1 Theoretical Sampling

Consistent with the abductive reasoning that is characteristic of the GT process theoretical sampling, *‘involves starting with data, constructing tentative ideas about data, and then examining these ideas through further empirical inquiry’* (Charmaz, 2006, p. 102). In other words, it consists of seeking relevant data that help researchers to elaborate and refine those tentative categories that may shape the theory.

This sampling method involves the selection of initial participants and the analysis of early interviews in order to inform the selection of both prospective participants and the topics to be explored. It is an emergent process so the researcher does not fully know which ideas need to be sampled until beginning the analysis, although these may have been informed by prior sensitising concepts (Charmaz, 2006). Sampling procedures may consist of studying documents, conducting observations, interviewing new participants and re-interviewing previous ones. The choice of what to look for and how to explore it will depend on purpose and intent (Charmaz, 2006). Later sampling is always guided by concepts and constructs that are meaningful for theory development (Strauss and Corbin, 1990; Gerrish and Lacey, 2008).

This process is repeated until no categories emerge, so called ‘theoretical saturation’. Therefore the size and characteristics of the study sample are not entirely decided in advance, but determined when theoretical saturation is reached; that is, when data do not provide any new theoretical ideas or do not add new properties to existing categories (Baker et al., 1992; Charmaz, 2006). ‘Theoretical saturation’ does not mean exhaustion of data sources rather than full development of categories. Therefore it is not a purely ‘objective indicator’ but depends on the confidence of the researcher that they have produced a thoughtful understanding and complete description of the phenomenon (Morse and Richards, 2002).

Building on the above, the research design for the present study was like a spiral. The selection of the first families was intentional, identifying key participants that I believed could provide a rich explanation of the phenomenon under study. However, as the investigation progressed the type of informants and the new scenarios to be explored were theoretically guided. ‘Memo-writing’ about codes and intriguing categories helped me to ponder where I should go and what I should ask families in order to increase understanding of the processes I was identifying and how they developed and changed. Thus I moved back and forward between data collection and data analysis, trying to advance my analytical thinking, (re)-define the properties of the categories and clarify the relations among them until the progressive densification and emergence of the substantive theory (Coyne, 1997; Charmaz, 2006).

4.3.2 Constant–Comparative Method (CCM)

In seeking to generate a theory, the researcher develops and manages abstract categories and relationships between them, working with ‘theoretical sampling’ and what is called the ‘constant-comparative method’ (Glaser and Strauss, 1967). CCM is a process of systematic analysis, based on the simultaneous collection and analysis of data, to develop concepts and categories emerging from the data. This analytical technique is a dynamic and systematic process of data codification which comprises the fragmentation, conceptualization, reduction and integration of data to construct a model.

During the analytical process the researcher compares data against data, across and between participants, categories, themes and incidents. Sequential comparisons are also carried in which data from prior interviews is judged against data provided by subsequent interviews with same participants (Charmaz, 2006). Concepts and ideas developed are also contrasted with other concepts and ideas. Thus the researcher establishes commonalities, divergences and relationships between them and finally generates comprehensive theoretical categories that capture and explain the phenomenon.

4.3.3 Abductive Reasoning

Grounded theorists follow the iterative logic of abduction through which they check and refine the development of categories. At the beginning, when an initial finding arises, the researcher considers all conceivable theoretical ideas that may possibly account for the finding, then returns to the field and gathers more data to put these ideas to test and subsequently adopts the most plausible theoretical interpretation (Charmaz, 2009). Namely, he or she produces logical but creative conjectures from data that examine possibilities until arriving at a plausible theoretical explanation of the phenomenon. This process underlies the GT iterative course of moving back and forth between data and conceptualization.

4.3.4 Active Role of Participants

Following the foundational assumption of constructivist inquiry that all the stakeholders should be part of the process of knowledge production (Nolan et al., 2003), engagement of participants in the interpretation and analysis of the data is particularly important. Thus in this study there was a continuum of participant involvement.

For instance, as a part of this co-construction of knowledge, participants get constantly involved in data analysis to ensure that the findings represent a shared creation (Charmaz, 2000). For that purpose the researcher may ask participants for feedback on major findings. This constitutes a great opportunity to receive useful and interesting contributions which elaborated upon the findings. ‘Co-construction’ does not only involve participants in data analysis but also forms part of the member checking process in which data, analytic categories and interpretations are probed with participants to verify the findings and the emerging theory and ensure that a good quality GT is produced (Lincoln and Guba, 1985).

Considering that the credibility of a GT study is concerned with the extent to which the association between the data and the research conclusions are strong and logical, and the extent to which the researcher accurately interprets the collected data as viewed by participants (Charmaz, 2006), the researcher encourages an active negotiation between himself and the participants so that the emerging theory is based on shared efforts. Participant feedback should suggest that the processes and factors described in theory made sense to them and they could be recognized in their daily life. To achieve this end the language used to describe key processes in the theory should be accessible to all people involved.

4.4. Implementing GT Methods in this Study

This section offers a detailed explanation of how GT methods were implemented in the present study. It follows the standard process of qualitative research, starting with the definition of the sample and sampling strategy, followed by the process of data collection and analysis, and concluding with some reflective thoughts on the ethics and quality of the study.

4.4.1 Research Context and Study Setting

As mentioned in the Introduction, the study was carried out in the capital city of the Autonomous Region of Navarra, Spain, and data were gathered from families living across that area. Originally I contacted the Association of Relatives of People with Alzheimer's Disease of Navarra (AFAN) to negotiate access to prospective participant families that used the organization’s services. This initial consideration was based on the knowledge that AFAN is considered a fundamental resource for families living with AD in Navarra, providing family support to about 600 families living in the region in 2012. The organization was constituted in 1990 with the objective of helping family’s carers of people with Alzheimer. Since then several support services for the family have been developed, including individual psychological assistance and family support groups. In addition, the organization raises community awareness of the disease through information campaigns and training sessions/conferences for professionals, families and the general public.

Unfortunately following an initial meeting with the head of the association and the psychologist it was concluded that there were few, if any, families who contacted the association during the early stages of the disease. Referrals and contacts to the association were usually at a later stage of the AD process. Thus, the standard profile of families attended was those who were in a middle-advanced stage of the disease. During the encounter the psychologist also informed me that they had limited contact with the person with dementia since their primary focus was on the main caregiver. Nevertheless, the association would be interested in collaborating if new families who meet the inclusion criteria for the study (described below) emerged. Thus the relationship with the society continued throughout the course of the study, which ultimately facilitated the possibility of conducting three focus groups with different family members, who had already gone through the experience of early AD. This strategy was implemented in the later stage of the research. It aimed to ascertain if the emerging theory made sense to other families living in similar situations whilst also providing an opportunity to hear new stories that nurtured the theory. A more detailed explanation of this strategy is provided later.

Thereafter I contacted the Memory Unit at San Francisco Javier Psychogeriatric Centre. This service was selected on both theoretical and pragmatic grounds. From a theoretical standpoint, this unit is considered the regional reference centre for treatment and care of people with cognitive impairment and early stage dementia. It emerged from the Navarra Health Care Plan (2001-2005) that raised the need for a protocol in primary care, which enabled the early diagnosis of Alzheimer's and other dementias. The Memory Unit is one of the programmes offered by the SFJ Psychogeriatric day-care centre which in turn consists of two sub-programmes for people with early stage of dementia: -the cognitive assessment programme and –cognitive stimulation therapy aimed at preventing the disease´s progression and relieving its symptoms. It provides support to about 290 people with AD and their carers per year from urban and rural areas. Both users of the public health care system and private institutions may be referred to the Unit. Therefore it would allow me to uncover a variety of different perspectives and develop a theory which accounted for a range of experiences.

Pragmatically a relationship with the institution already existed as a result of an earlier research project conducted by the School of Nursing of the University of Navarra. So both the unit manager and professionals were already familiar with us and the type of research we undertook, which facilitate their participation and access to potential participants.

4.4.2 Access: Sample and Sampling

In qualitative research sampling strategies are not subject to probabilistic procedures; the focus is not on identifying the total population, events and context to develop a sampling framework. Rather sampling seeks to identify individuals, contexts and key events that provide valuable information related to the research question(s) (Gerrish and Lacey, 2008).

I therefore used a combination of purposive and theoretical sampling. I initially used a purposive sampling strategy to select subjects who represented the target population in respect of their familiarity and knowledge about the phenomenon. Families who, because of their experience of the phenomenon, were thought to be key players in sharing their life experience with AD were initially contacted, see below for further details of how this took place. Subsequently ongoing theoretical sampling was employed (see later).

Study Participants

In the current study, participants comprised older people with early AD and their families. They were eligible for recruitment into this study providing they meet the following criteria:

People with AD

- People aged 65 and over (this is the age range recognized by the UN for older people in developed countries) of either gender who lived at home, either with or with the support of family members.

- Only people with a diagnosis of suspected Alzheimer´s disease established by clinical examination, the Mini-Mental State Examination (MMSE), and confirmed by neuropsychological tests were included in the study. Judgements about their suitability for the study were also informed by discussions with professionals at the centre who knew these people well. Professional judgements were made based on the person´s adjustment and willingness to talk about their memory loss; level of competence and ability to understand and give informed consent; and retained verbal fluency and level of concentration. The views of people with AD were essential in obtaining a real understanding of how it affects people´s life and experiences.

- The person with AD was at an early-mild stage of the disease, which allowed us to explore the early impact on the family and ensured that the person affected could play an active role in the interviews (Snyder, 2001). Hence the person with AD was able to give informed consent and engage in the conversations. This is later considered in depth.

Family

- The family supported a relative with AD either in the person's or their own home. It was not necessary that each family member lived with the person with AD but they lived close enough to assume a share of care activities or were deemed by the person with AD to provide them with important sources of support. Families should be in the early stages of supporting the person. The sample comprised a mixture of spouses, husbands, adult children and significant others.

Access to Participants

Once access was granted by the head of the memory unit, participants who fulfilled the inclusion criteria and might be interested in taking part in the study were identified by professionals at the centre, especially by the nurse who had direct contact with the person with AD and relatives. Before contacting potential participants I met the nurse to carefully discuss the study and the selection criteria. I also provided her (and the institution) with a written summary of the study so that it could be of help when she informed families (Appendix 4.1).

The nurse contacted potential participant families by phone and briefly explained the study to them. If the family showed interest in the study, an initial meeting was arranged, in which both the person with AD and the family were present. As far as possible those meetings coincided with days in which the person with AD attended some cognitive training sessions. During the meeting I verbally informed the family and provided them with written information about the study, its methods and the voluntary nature of participation, giving them the opportunity to ask questions and clarify aspects of the study (Appendix 4.2 and 4.3). The information was provided to both parties (the person with AD and other family members) ensuring everyone understood the study objectives and the implications of taking part of it, so they could make an informed decision. The information sheet contained the same information for both parties, with minor differences in style. Verbal explanations of the study were adapted according to personal characteristics to facilitate understanding without missing any information.

Subsequently the first interview was arranged with those families that met the inclusion criteria and decided to participate. The date, time and location of the encounters were chosen according to availability and preference of participants, offering them the possibility of conducting the interview at home or in a room of the Memory Unit. Except for one family, all interviews were completed at home which allowed me to get an understanding of the home environment, as well as making participants feel more relaxed. Prior to the interview participants were once again informed about the study and its voluntary nature was reaffirmed. All the participants had the right to withdraw from the study at any time without detriment of any kind. Assurance regarding confidentiality and anonymity was also given. Signed written consent was obtained from participants as well as authorization for audio-recording the interview (Appendix 4.4 and 4.5). As participants were interviewed on more than one occasion informed consent was seen as a dynamic and ongoing process between myself and the participants (Seymour and Ingleton, 1999).

Sampling the ‘Whole’ Family

As was discussed in the previous chapter most research on family experiences of living with AD starts from dyadic perspective with attention given primarily to the affected person and the primary caregiver. Few studies have adopted a family system approach that addresses the experiences of the whole family, this was something I wanted to address. The simultaneous interest on each person both as an individual and a family member required having multiple members of the family as informants (Robinson, 1995). As it will be seen recruiting every member of the family was not possible, the interviews provided a broad perspective on the experiences as a whole.

4.4.3 Data Collection

In-depth Interview

The primary method of data collection in this study was in-depth interviews. These allow the researcher to glean as much information as possible from interviewees with the aim of gaining the fullest understanding of what it is actually like for them living in the situation under study (Taylor and Bogan, 1998). Importantly in-depth interviews also allow participants to ‘speak for themselves’ and thus increase their meaningful participation in the study.

I therefore conducted in-depth (family) interviews using open-ended questions to gather detailed information about families living with AD, their contexts and situations, from their own perspective and using their own words and expressions. I sought to discover perceptions, beliefs, feelings, thoughts, processes and meaning through their narratives and interactions.

A relatively un-structured interview guide was developed based on the study objectives and the initial sensitising concepts. The themes to be covered, the level of detail and the clarity of questions were discussed with supervisors. Subsequently the interview guide was translated into Spanish. The interview process followed a temporal perspective beginning with the onset of memory loss and exploring events since that time. However, family members and people with AD were free to discuss any issues that they considered relevant. That is, interviews were conversational in style to facilitate a relaxed and enquiring atmosphere through which to enable participants to feel comfortable to talk about their experiences. Consequently, although interview guides were written, these were used more as a prompt for the interviewer than a rigid format to follow. As such they explored a number of topics and themes rather than following a set order or number of questions. These guides evolved as the study progressed and theoretical sampling was applied.

A list of open-ended broad topic areas was elaborated (Appendix 4.6) including questions such as:

- *To start, could you tell me about when these (your/ your relatives’) ‘memory loss’ episodes started and how did you notice them?*
- *How did you feel about?*
- *What do you think about these episodes?*
- *Could you tell me if there have been any changes in your (daily) life since then?*

- *In your opinion, has this affected your family life?*
- *What are the main challenges you all are facing?*

Using these general questions I tried to put participants' experiences into context and encouraged them to tell their stories in a narrative and interactive fashion, rather than providing one-word responses such as 'yes' or 'no'. These questions elicited unstructured (but related) responses from participants that allowed me to explore what was significant for them rather impose my own ideas.

I prompted and probed deeper into the participant's situation and asked them more detailed questions. When I felt that participants started giving 'yes' or 'no' responses I changed to questions such as: *'Please tell me more about…'; 'could you expand on your answer';* '*could you give me a specific example of...?'*. This allowed me to get more details from the participants (Taylor and Bogdam, 1984). My communication skills were important in making the in-depth interview a productive process and in conducting the interviews I paid close attention not to make value judgments but showed interest and empathy to what participants were sharing with me (Taylor and Bogdan, 1998). These questions raised conversations around the family unit, its composition, relationships and family members' involvement that provide me with significant insights into the whole family system. Although interviewing every family member was not possible I still felt that members provided insights into the views of those I could not talk to, albeit from their own perspective.

Demographic questions (such as age, gender, residence, diagnosis, family structure relationships etc.) were also collected in a standardized demographic-data sheet that was completed at the beginning of each interview (Appendix 4.7).

One of my supervisors, with broad experience of undertaking family interviews, attended the first two encounters to provide subsequent advice/guidance if needed. Subsequently we both shared impressions and reflected on the role I played as interviewer, my attitude, how I posed the questions and the general dynamic of the conversation. This helped me to better prepare for subsequent interviews, especially those with the whole family, and provided me with valuable feedback on issues such as, avoiding asking several question at once and balancing the contributions of the family members. Initially some family members adopted a dominant role in the interview but this improved in future interviews as I tried to ensure that everyone had the chance to contribute, by asking questions such as: *what do you (other member) think about that? Would you (others) like to expand on this point (previously brought up by other member of the family)?*

These initial interviews also provided important insights into the data collection method. Participants were also asked if questions were clear and easily understood and if the interview was too long or taxing. Participants stated that they enjoyed sharing their experiences and were pleased to take part in the study. The interviews were seen by the families as an opportunity to sit and together talk about particular topics. Although the aim of the interviews was not therapeutic in itself they contributed to the sharing feelings and information within the family, and helped to create shared meaning about the AD and the family care process.

Some changes were made into the interview guide following the two first interviews. For example, I realized that the first question about the 'memory loss episodes' was sudden, mainly for the person with AD. So in the following interviews I started by informally asking about the memory unit programme and why they attended there. This question allowed me to identify: the level of awareness the person with AD had about the situation; how he/she referred to it ('head in the clouds', 'little forgetfulness'); and the shared understanding within the family. Thenceforth I adopted the language participants used to refer to the condition. Similarly more concise and simple questions were developed in order to make the interview questions more approachable and suitable for the participants, especially for people with AD.

Ongoing adjustment to the interview schedule occurred throughout the whole process of data collection. Thus the content of the interview was modified and directed to topics that were relevant for the theory development. The new questions and topics were jointly reviewed by supervisors who previously examined the results of the analysis so they were able to assess the adequacy and consistency of the questions in light of the analytical work. The section on theoretical sampling later in the chapter explains how the interview process varied as the research progressed.

The Interview Process

The interviews were conducted at a time and place of the participant's choice. In most cases the interviews took place at home where participants seemed to feel more comfortable. One family preferred to meet in the Memory Unit where interviews took place in a quiet room, with little chance of being disturbed and where privacy was provided for the participants to openly share their experiences and perceptions.

The interviews lasted between 35 and 90 minutes depending on the number of interviewees at a time and the progression of family encounters. Family interviews tended to be longer than those in which only one member of the family was involved. Moreover, the first meetings with families were generally lengthier compared to the subsequent ones, where there was a more familiar relationship between the interviewees and me.

All the interviews were recorded with the participants' permission and transcribed verbatim. Recording the interviews allowed me to maintain eye contact and observe facial expressions, while concentrating on the participant's responses. Every transcription was subsequently checked against the recording, before proceeding to data analysis.

Consistent with the principle of a constructivist interview, family members were encouraged to freely discuss topics they considered to be the most significant for them. Likewise I tried to ensure that an understanding of the study phenomenon was jointly constructed by both participants and me (Rodwell, 1998). To achieve this I rephrased what participants said during our conversations to check my interpretation and reflected my understanding back to them. I also provided a brief summary of the major ideas towards the end of the interview to corroborate my understanding and stimulate further discussion if required. I asked participants whether there was anything else which they thought I should know to better understand their own experiences or whether there was anything important that they would like to share. These final questions proved very useful, as the participants’ answers were fruitful and often produced additional important insights into the research question. When I thought that participants struggled to answer some questions I shared some of my own family’s experiences in living with AD. These strategies not only provided a way of creating a ‘joint’ understanding with participants, but also enabled the conversation to flow easily and helped me establish a partnership with the families.

Support was provided to those participants that became distressed or felt discomfort when talking about sensitive issues. I tried to comfort them by holding their hand and allowing them time to recover. Similarly when tensions and controversy between family members arose I promoted dialogue and listening, always avoiding being seen to ‘take sides’. There was a particularly tense situation during one of the combined family interviews. At that time I decided to turn off the recorder and allowed the family privacy to clear the matter up. Slightly later the family members involved showed me their appreciation for the respectful action and maintained a very more trusting attitude throughout the study.

As a part of the process issues that emerged during the first interviews and were felt to be particularly important were incorporated into subsequent interviews and raised with the participants (Rodwell, 1998). Hence a series of interviews was undertaken involving the same family on three or more occasions. In preparation for conducting successive interviews with the same family, I listened to digital files of previous interviews many times and reviewed transcripts, field notes, memos and any other relevant information in order to refresh my memory and develop subsequent questions. This practice enhanced my sensitivity during consecutive interviews, demonstrating respect for participants by accurate recall of their earlier responses. In successive interviews I provided participants with brief summaries of earliest interviews, including textual quotations, to exemplify the processes I wanted to further explore and to put in context the questions I posed to them.

Involving People with AD in Research

The importance of involving people with dementia within qualitative research studies in a meaningful way is increasingly recognised in order to ensure that their voices are heard and their experience of living with this condition is captured using personal accounts (Wilkinson 2002; Moore and Hollet, 2003). Such involvement is seen as transformative for both PWD and others as hearing and attending to such voices may, by enhancing understanding of the condition, challenge stereotypes and change attitudes, whilst also according value to the person affected (Sabat, 2003). To make this a reality Hellström et al. (2007) contend that the central question is not whether to include PWD but how can this best be achieved. Inclusion therefore presents both challenges and opportunities for researchers.

The section below considers how this, with particular attention to the interview process, was achieved in the present study. The consenting process, specially the way the consent was sought, gained and checked throughout the study will be further addressed on the ‘ethical issues in conducting the study’ section.

From the outset establishing rapport with participants was a central concern. Whilst important for all participants it was particularly significant while interviewing people with AD. Time was taken to build good relationships based on warmth and empathy and, to ensure that people felt emotionally safe to be able to talk about their views, feelings and experiences. Hubbard et al. (2003) acknowledge the importance of taking time, building a relationship, being flexible, being informed about the participants through prior discussion with carers and significant others, and developing bespoke method of data collection as key strategies for maximising the response of people with dementia and enriching their participation in research.

In this regard, during the early interview process ice-breaker conversations were used as an effective way of putting the person with AD at ease and allowing me to establish relationship with the person in advance of the ‘interview’ itself (Nygard, 2006). To achieve this we spent few minutes talking about pleasant and relaxing topics. In subsequent interviews I used the knowledge I had obtained earlier to engage the person and further build up a trusting relationship (Hubbard et al., 2003). For instance one woman was very proud of how she looked so the second time I met her I admired the dress she wore that day and we exchanged views on textile design. Through expressing interest in her and sharing thoughts we developed a good rapport quite quickly at each interview. I also found that their attendance at the memory unit programne was something that people with AD valued positively, as they enjoyed talking about the activities they did and the people they met. Talking to them about their experiences at the unit allowed me to broach the subject of ‘memory loss’ in a relaxed way. Rapport was further enhanced as I interviewed participants on more than one occasion. Furthermore talking to the family allowed me to get a more complete picture of the person with AD which was then used to help me start the encounters with the person with AD in an appropriate way (Lloyd et al., 2006; Nygard, 2006).

In addition during the interviews I maintained eye contact, used a calm voice and was an attentive listener (Bourgeois, 2002). In this way I felt that people with AD understood my desire to explore their experiences in a respectful way. All of this helped me to create a safe and relaxed atmosphere for them to express their thoughts openly (Hellström et al., 2007). If I noticed any potential misunderstandings I rephrased the question to ensure it was understood by the participant (Moore and Hollett, 2003). Additionally I allowed people plenty of time to respond. It was also important to observe participants’ nonverbal language for signs of fatigue or unease during the interview (Moore and Hollett, 2003; Hubbard et al., 2003). When this occurred I offered the participant the choice of continuing or stopping the interview.

As with the interviews with the rest of the family, special attention was given to the way that the interview with the person with AD was concluded. As Hellström et al. (2007) suggest it is particularly important to ensure that people with AD feels they have positively contributed to the interview to avoid leaving them feeling let down. I made sure that I thanked the person with AD and that they knew that they had made an important contribution to the study. In this way I believed that they left the interview with a positive feeling about both themselves and our conversation.

Individual and Group Encounters

Given the potentially sensitive nature of some topics addressed participants views on whether to hold joint or separate interviews varied. Such decisions were made following discussion with the family involved. All families were jointly interviewed at least once. Individual encounters were conducted with 5 of the 7 people with AD involved and the rest of relatives separately.

There are potential advantages and disadvantages to both individual and group encounters. Interviews with the 'whole' family provided relevant information about how the family as a whole constructed meaning, the extent to which family members agreed or disagreed about something and how the family thought and acted as a social group. However, during some encounters it was perceived that they could not always express their views openly and freely and wanted to have individual interviews. The principal reasons were:

- There were different levels of acknowledgement and awareness of the disease and the care requirements.
- The normal communication pattern of the family was difficult in itself (previous family conflicts).
- Different perspectives and positions among family members induced family arguments that might affect their relationship.

Individual interviews provided better understanding of the meaning events from differing perspectives in the family and the exploration of sensitive topics that individuals were unwilling to speak of in front of others. Nevertheless at these meetings it was important to 'think family' by asking questions that included other family members, such us *what do you think 'your relative' thinks about this issue?* This helped me to shift the individual focus of the interview toward one that draw forth family data.

Writing Field-notes

Field-notes are written comments that the researcher creates during the process of collecting or conceptualizing data and serve to document what they think is taking place in the setting, and the events that he/she hears, sees, experiences and thinks about. They are written during or very close to the completion of fieldwork and reflect the biases, reactions and problems the researcher found in the process (Gerrish and Lacey, 2008). Field notes might be use at later stage of the research to help the researcher remember important issues and questions.

Field-notes are often employed to complement interviews and to place interview data within a given context such as the setting, the impressions the interviewer gained, and the non-verbal communication during the interaction with the interviewee (Rodgers and Cowles, 1993). They are also considered as the necessary link between empirical and theoretical work as they capture the sequence of activity and reflect the internal dialogue between the researcher and what he/ she observes, knows and interprets.

In the current study, field notes were collected immediately following each interview. The main purpose was to record significant information and so facilitate interpretation of the data, which included descriptive information about the date, time and length of the interview, the number of people interviewed and the context and characteristics of the interview venue. The non-verbal communication of the participants, the feelings expressed and any significant events were also recorded together with my thoughts, ideas and impressions regarding the interview and the interviewed.

Some thought about my interventions during the interviews were also documented and contrasted with the audio records. I discussed these perceptions with the supervisory team in order to get some advice and generate discussion on how this may impact in my data collection process and the research process.

The Logistics of Data Collection

Data collection for the study consisted of interviewing seven families (22 participants and a total of 26 interviews) living with early stage AD, originally selected purposively through the Memory Unit. The process followed an iterative design (follow up) with a series of interviews being developed with each of the seven families. This met the rationale of constructivist research approach on gathering extensive rich data about the participant´s lives and words through sustained interaction rather than limited interviews or isolated encounters (Bryant and Charmaz, 2007). Having repeated contacts over time with families not only contributed to establishing rapport but gave me the opportunity to develop a detail understanding of each families experience and perspective (Taylor and Bogdan, 1998).

Initially three families were recruited, including three people with AD (1 man and 2 women) and nine relatives (1 wife, 1 husband and 7 daughters) to participate in the study. While two of the families decided to be interviewed together, the other was interviewed separately. In this case the family said that they lived in a 'complex' situation so they preferred individual interviews. All the interviews took place at home, following family's preferences, except for the first individual interview with the person with AD which was conducted in a comfortable and quite room of the Memory Unit, after the cognitive training session the participant attended. I completed two interviews with the whole family, one individual interview with the person with AD alone and two encounters with relatives (see appendix 4.8).

Preliminary findings from an initial analysis of the data guide theoretical sampling of new family participants and phenomena or situations. Thus I went back to the research setting to further explore relevant and emerging themes. I shaped and (re)shaped data collection with the intention of refining data and increasing knowledge and understanding, according to the tenets of grounded theory. I carried out theoretical sampling in order to collect data to delineate, develop and improve emerging categories. Thereby the data collection process was extended and comprised (see appendix 4.8):

- Completing seven more interviews with two of the three initial families (two individual interviews with people with AD, one family group interview and four individual encounters with relatives).

- Recruiting new families (4), including four people with AD (a man and three women) and six relatives (a son, a "stepdaughter" and four daughters).

Thirteen in-depth family interviews were carried out (five group interviews, two individual interviews with people with AD and six individual encounters with relatives)

- Conducting three focus groups with 14 relatives of people with mid-advance stage of AD that attended the regional association (AFAN) (see later for a fuller description).

The final round of data collection was designed to enable the emerging (not yet fully defined) theory to be ‘checked out’ with the existing sample as well as with new family caregivers who had already experienced the first stage of the condition. It provided the opportunity for data collection to clarify and expand categories if needed, and to further explore their properties and the relationships between them.

Theoretical Sampling

Consistent with one of the fundamental principles of GT studies (theoretical sampling) preliminary analysis of data guided subsequent data collection for the study. Therefore sampling of both participating families and events were informed by a simultaneous process of prior data collection and constant comparative analysis.

For example, initial analysis suggested that family composition and relationships might significantly affect the care dynamics (such as a protective attitude) and the experience of change within the family. Thus new families with different structures and connections were recruited (e.g. male caregiver experience, extended family experience, no partner in the family).

Since theoretical sampling is not just concerned with who and where to sample but also what areas to explore, the interview processes also evolved according to data analysis. As previously mentioned the initial interviews were structured around open questions followed by discursive exploration of the issues raised using prompts. In subsequent data collection open questions were again used at the beginning of the interviews. But questions were also added which reflected emerging themes if these had not been mentioned spontaneously by the participants. That is, although my initial questions were guided by sensitising concepts, I also pursued other topics that participant families were defining as relevant. For instance, I was prompted to explore the process of disclosing and sharing the diagnosis both within the family and with other people, something I did identify in advance. I used questions such as: *Have you talked about this (the condition, some symptoms and lived episodes) with someone in the family? How you refer to it within the family?* Likewise I further explored the family's perceptions of the professional support they received as this emerged strongly from the initial interviews.

I used the successive periods of data collection to further elaborate upon emerging major categories, which ultimately comprised stages of a temporal model. Furthermore conducting a series of successive interviews with the same family allowed me to gain a deeper understanding of the nature of resulting family processes such as *'noticing'*, *'redefining'* and *'balancing'* (see findings chapters), when and how these occurred and how the family worked.

For example, *'noticing'* was the first category identified by examining the family accounts on how they first experienced the condition. Data suggested it was not a static action but a process that developed over time. This temporal and transitional dimension was further elaborated upon in subsequent interviews with the families. This will be also illustrated more fully in the analysis section.

Based on the initial accounts of families I went back to them and asked them specific questions I had not covered before about the type of changes that occurred (internal and external structures, instrumental functioning, expressive patterns...), the meaning those changes had for the family and the way the family worked to adapt to them. I asked myself questions such as: *how the meaning that AD has for the family affected the way the family perceived changes and reacts to them? How those changes influenced the way the families see themselves at present? Did the perception of change depend on the degree of control that the family had/ desired on the situation?* Then I examined old and new statements, events and cases that illuminated the emergence of a more advanced category named *'Our life is changing'* which comprised the family process of *'redefining*. In attempting to gain a more complete understanding of this process I returned to the families for further questioning.

Data collection continued until data saturation was reached, this being the point at which either no new information about the participants' experiences could be discovered or no new insights into the understanding of the family process involved in living with early AD emerged.

4.4.4 Data Analysis

As exemplified above data collection and analysis have an iterative relationship in GT so that each informs the other. During analysis the researcher maintains an on-going dialogue with data through the use of the constant comparative method that is used to elaborate codes and develop construct/categories upon which the emergent theory is based (Backman and Kyngäs, 1999).

Data analysis comprised different but interrelated stages. During the first initial coding, I explored all the possibilities within the data by remaining very close to the line-by-by line meaning within them (Charmaz, 2006). This initial stage informed decisions about later data collection and analysis. Once the initial phase finished, coding became a more focused and conceptual process. At this stage I used the most significant initial codes to filter data in order to begin to develop categories and reduce the number of codes. Using the constant comparative method both new and prior data were considered again using the emerging categories so that new categories and their properties were created. I started to establish conceptual links between categories and their properties. If the relations established were thought to be insufficient theoretical sampling continued, seeking new information that helped to expand the emerging concepts and to clarify the developing theory. The relationships between categories were then explored through theoretical ideas to assist the development of a coherent analytical history of the data (Charmaz, 2006). Finally, after the reduction of the categories, I refined and described the key processes that constitute the emerging theoretical model.

Data Preparation

Prior to data analysis the recording of the interviews were transcribed verbatim, which means that nothing was rephrased, altered or omitted. Expressions such as laugher, crying and silence were also included in the transcripts since they provided significant information on the expressive part of the participants. In addition I closely examined each transcription against the recording to ensure that the text was accurate and there was no missing words or information.

Although the data analysis was carried out according to the original transcripts and therefore the original language (Spanish), some parts of the interview transcripts were translated into English by me for discussion with the whole supervisory team. The translations were revised by an experienced bilingual person to make sure that they kept the same meaning.

These parts that were selected were those that, following discussions with the supervisor and work team of Spain, generated controversy or played a key role on supporting the analytical product. Thus, large amounts of data were translated during the initial phase of analysis to ensure that the process was being carried out in agreement with all concerned. Similarly, when new codes and categories emerged or data analysis took a significant or new direction, scenarios and extracts that illustrated this were translated for reflection and feedback.

Using NVivo

Data analysis was assisted by QRS NVivo (v8.0), a computer software package specifically designed for qualitative data analysis originally with grounded theory in mind (Bringer et al., 2004; Gibbs, 2002), for which training was undertaken. This software was chosen for its flexibility and lack of constraint on the researcher’s analytical processes, whilst providing a means of storing, sorting and resorting data.

NVivo allowed creating and appending codes (nodes) to data segments of any size. At the beginning a list of nodes was created and recorded as ‘free’ nodes. Access to the content of nodes was possible at any time which facilitated the constant comparative process of comparing within and between codes and the identification of properties and relationships between nodes. When relationships were identified nodes were clustered into groups (trees) so that each one had as many or as few descendent nodes or parallel nodes as desired. The trees represented the emerging categories, and their descendents and parallels worked as their properties and dimensions. Codes drawn directly from data appeared in brackets, making reference to the 'in-vivo' codes.

NVivo worked well in the early stages of analysis as it provided a valuable tool for sorting, comparing incident with incident within and between transcripts and recording progress. The 'tree' function was useful in recording relationships between codes and identifying emerging categories. However, as the conceptual level of analysis increased, hard copies of transcripts and node content were found more useful in identifying processes occurring in the data.

NVivo software was principally used for data management and as a repository for records of analytical work; which means that the qualitative analysis was not completed by the software but by the researcher, since the former is not capable of interpreting judgments neither determining the relationships between categories (Welsh, 2002).

Coding

According to Charmaz (2006) coding is considered '*the pivotal link between collecting data and developing an emerging theory to explain these data. Through coding, you define what is happening in the data and begin to grapple with what it means'* (p.46).

The logic of grounded theory coding differs from quantitative logic methods that apply preconceived codes to the data. In this case, I created codes by defining what I observed in the data. Thus the codes emerged as a result of examining the data and defining their meanings (Charmaz, 2006). Through this active process I interacted with data over and over again and I constantly asked myself different reflective and analytical questions.

Although the study objectives had identified domains and topics to investigate, codes arouse directly from the analysis of the raw data, not from priori expectations or models (Thomas, 2006). In assisting this analytical process the following questions were used (Gibson and Brown, 2009):

- What are my main areas of interest, or themes?
- What kind of picture am I developing through my codes and categories?
- What is the relevance of this code to my research question?
- What kind of analytical work does this code provide that that one doesn´t?
- What is the relationship between this code and my initial conceptualization of the phenomenon?
- How does it help me to understand what I am seeing?

The sensitising concepts were used to guide initial analysis (Charmaz, 2006), providing tentative tools to develop my ideas about what I was seeing in the data.

For example I was particularly attuned and sensitive to the effect that the disease and the care process may have on the dynamic and functions of the family. Thus, I started with my research interest in identifying the changes that occurred in the family lifestyle, but also explored the way that families learned and worked to cope with change.

Similarly the (initially ‘static’) idea of ‘needs and gains in family care’ gave me a starting point for initiating codification. However it did not determine the content of the analysis but provided a fruitful direction toward the development of the idea of families ‘*maintaining a balance’* (positive dimension) which at some stage was not possible to achieve and things started to *‘fall apart’* (negative dimension) (see findings chapter).

Initial Codification

Initial coding was aimed at developing a set of codes that labelled the key points being made by the participants. For that purpose the interview transcripts were reviewed, working at the most concrete level. I started the process with a close listening and readings of the records and transcripts until I was very familiar with the content of the interviews. Once I did it, I highlighted those words, expressions, phrases and text segments that I identified as meaningful units, and elaborated codes to name them. I used gerunds, nouns formed from a verb denoting an action or state, to produce codes and kept close to the words that participants used in their narratives. Using gerunds helped me to concentrate on identifying meaning and actions, how people enact or respond to certain events and what meaning they hold. My activity at this point was mainly focused on separating data and identifying significant processes and actions in each segment of data.

In assisting this process some reflective questions were used (Charmaz, 2006, p.51):

- What process is at issue here?
- How can I define it?
- How does this process develop?
- How do the study participant(s) act while involved in this process?
- What do the study participant(s) profess to think and feel while involved in this process?
- What might his or she observed behaviour indicate?
- When, why, and how does the process change?
- What are the consequences of the process?

Strategies such as word by word, line by line and incident by incident coding were implemented at this stage of the analysis. Since there were huge amount of data to code, the majority of the interview transcripts were coded line by line, segment by segment or incident by incident (see Appendix 4.9 for an example of preliminary codes). Along with these practices 'in-vivo' codes were used as much as possible, keeping the same word that participants used to refer to and describe their experience. This strategy helped me to preserve participant´s meaning of their views and actions and reduce the imposition of my own bias. I carefully considered these types of codes because as Charmaz (2006) suggests, they cover assumptions, behaviours and imperatives that frame meaning and action.

Initial coding was facilitated by my immersion in the data. Through comparing data with data, and family narratives across and within families, I identified relevant concepts and began to see larger processes that were further explored.

Focused Coding

The next stage of coding, focused coding, took the comparative process a step further. As my analytical work progressed I began to deal with what the codes meant and what they represented. I used the most frequent and/or significant codes to sort and synthesize larger segments data. At this point I needed to decide which of the initial codes provided most analytical sense in classifying and clarifying meaning in the data. For this purpose quite a few meetings and consultations were held with the supervisory team, either face to face or by email.

A number of focused codes emerged (see Appendix 4.10 for an example of focused codes) that helped me to define key ideas in the participants' narratives. Then I engaged in constant comparisons between my codes and data and conducted new interviews. I refined those codes through comparing my interpretations with data and participant´s actions. Gradually codes were shaped as theoretical elements of an 'emerging theory' and led to further data collection. By careful attention to the coding process I started knitting important yarns to the grounded theory.

Focused coding was not a linear process but an emergent and iterative one. I went back to the families and explored issues that were overlooked, too implicit to initially understand or had not been fully addressed yet. This allowed me to gain a deeper understanding of family processes and facilitated categorization and conceptualization of data. This theoretical integration continued over all subsequent analytical steps.

Through more detailed examination of focused codes and further comparative analysis I elaborated conceptual links that clustered and grouped concepts into similar themes and patterns. Thus I began to develop conceptual categories and relationships between them which led me to develop a temporal explanation of the family experience, composed of different stages. I looked for commonalities and differences between grouped concepts, which allowed me to define the dimensions of the formed stages (categories). Afterward they were examined against relevant data from different families' experiences. Since some stages and their component social processes needed further development and clarification I re-entered in the field and went back to the families to seek more data that focused on these issues. Thought this procedure I tried to clearly define and 'saturate' each of the stages of the temporal model that was grounded in the rich data.

Data analysis (and subsequent data collection) evolved until no new events or ideas emerged that could further the model's development. Thus the analytical work concluded with a three temporal stage model, underpinned by key social processes that provided an integrated interpretation and explanatory account of the entire body of data (Charmaz, 2006).

Memo-writing

Memo-writing is a central part of the analysis process. It serves as a means to reflect on the emerging ideas about the data and participants as well as on the meaning that the data have for both participants and researcher, thereby making visible the influences and experiences of both parties (Mills et al., 2006). According to Charmaz (2006), memo-writing enables the researcher to be continually involved in the analysis process from the beginning and throughout data collection. It invites the researcher to actively engage with the body of data to develop ideas and to fine-tune subsequent data collection. Through this strategy the researcher develops hypotheses about the properties of categories, relations between them and the possible criteria for selecting participants to gather innovative data that assists the development of the theory.

Initially I used memos to document hunches, questions and areas to explore during subsequent data collection. Gradually I wrote more analytic and abstract memos about concepts and emerging codes/categories. Through these I intended to explore the potential of some selected focused codes as tentative categories. I wrote conceptual memos about the initial and focused codes being developed. I used these memos to record my thoughts about the meaning of codes, how and when processes occurred and how they changed. I also used them to make comparisons between data, cases (across and within the families) and codes, in order to find similarities and differences and raised questions to be answered in successive interviews.

Writing memos kept me active in the analytical process and alerted me to some unresolved questions about the data (see Appendix 4.11 for an example of memo-writing). This strategy encouraged me to make systematic comparisons between data and conduct further interviews to illuminate the creation and development of final categories and processes

4.4.5 Co-construction of the Findings

In compliance with the constructivist approach adopted in the study I wanted to engage the participants in the interpretation and analysis of the data, and thus in the construction of theory. Although much of this occurred naturally as a part of the data collection process when I checked meanings as the interview progressed, particular strategies were also adopted. This are explained below.

Co-constructing With Participating Families

The development of a series of interviews with each family included in the study allowed me to involve the participants in generating findings during the whole data analysis process and ensure that the findings represented a shared construction (Charmaz, 2000). Co-construction of the theory involved member checking procedures in which data and analytic categories and interpretations were ‘checked’ with family members in order to ensure that a good quality GT was produced (Lincoln and Guba, 1985).

As well as the on-going process of co-construction I also arranged a final encounter with the families to present the major finding across the data as well as a particular case-study from their own experiences. To do so I drew up a time schedule of the main family processes identified and illustrated this with some interview quotes. I also verbally commented on the findings with the families, supported by visual representations using a slide show presentation program (see Appendix 4.12 for an example). This allowed me to present key findings to participants through concrete and particular examples. Families commented on the schemes and provided inputs that both corroborate the finding and enhanced the development of the final theory.

For example families expanded their experiences of *‘feeling abandoned’* by sharing new accounts on the limited professional support they received. This allowed me to reflect not only on the experiences and interactions with professionals during and close to the diagnosis period but also at critical points over time. Thus families new accounts revealed that *‘feeling abandoned’* extended along the whole process.

These meetings with each family also further expanded on how the family ‘worked’ together (or not) over time. Expressions like *‘this is a wheel’* or *‘the things stabilized, but now again…’* made more evident the dynamic character of the processes involved.

At the end of the encounters families were asked if they identified with the schedule and interpretations presented, to which all responded affirmatively and agreed on how their experiences were captured.

Co-constructing with New Family Caregivers of People with AD

Co-construction of the findings was also carried out with new family caregivers of people with AD. Here three focus groups were conducted with relatives of people with mid-advanced stage of AD that attended the regional association (AFAN). They were selected as it was thought that, being relatives whose loved one was in a mid-advanced stage of the disease their experiences could provide new insights into the study findings while also ascertaining if the processes identified made sense to them. This process is described below.

Focus Groups

Focus groups are considered advantageous to both learning about the experiences and views of a particular group of people on a topic and improving understanding of a specific topic through group interaction (Gerrish and Lacey, 2008) They allow participants to examine and discuss their experiences and opinions with respect to that topic. In this particular case family caregivers shared their own experiences and elaborated upon the study findings presented (the key family processes and the emerging theoretical model).

The main reasons that lead me to conduct focus groups were that:

- Focus groups may help to reveal consensus views, ‘verify’ research ideas of data gained through other research methods (in this case from previous family interviews) and thus add richness (Lewis, 1992).

- The researcher has less influence over a group, which limits the imposition of ideas (the emerging model) and encourages discussion.

- Focus groups, when carried out with ‘peers’, create a supportive environment in which to share experiences.

The composition and size of the focus groups are still controversial issues in the research literature. However, decisions should be based on the nature of the investigation, the purpose and the amount of time and resources available for the project.

Homogeneity of the focus group was not a key consideration but in this case all participants attended support groups of the association and therefore it was considered that they would feel comfortable talking to other caregivers. In the end two groups of daughters (the most numerous family member in the association) and a mixed group consisting of daughters and husbands were formed.

According to Gerrish and Lacey (2008) the size of the groups can generally vary between 5 and 12 members. In this case the groups were made up of 5 family members to ensure a diversity of experiences, but also give them the opportunity to fully participate in the discussion, since it was the depth of their contribution that was sought.

Prior to conducting the focus groups written consent was gained from participants (Appendix 4.13). Additionally permission to audio record participant´s conversation was also obtained since their experiences and comments were treated as data. Confidentiality and anonymity were also ensured.

Because of their wider experience it was challenging to keep their thoughts on the beginning of the experience, particularly when talking about professional support and care strategies. I had to be very careful about focussing discussion around the early stage experiences. The groups began with an oral presentation about the theory as it currently stood. The key family processes were presented in a temporal fashion and supported by examples elicited from the family interviews. During the presentation some questions about key process were posted to encourage group discussion.

The focus groups helped to expand on the process of *'noticing'* and particularly *'disagreeing'* activity in the family. Participants provided several accounts that illustrated how their families dealt with difficult situations when recognizing that something was 'wrong' with their relative and how this was confirmed. There was also considerable discussion around how to perceive and consider the future at that time.

My understanding of the dynamic nature of the processes involved was also enhanced, especially with respect to changes in family relationships. As with to the main study families, participants in the focus groups were asked if the processes and the overall model corresponded with their own experience, to which they responded affirmatively. Therefore the focus groups served to add to, expand, and refine the processes and the model that was being developed.

Theoretical Saturation

Theoretical saturation is usually seen as the end point of the GT process. However the extent to which theoretical saturation can be said to have been achieved has been questioned (Charmaz, 2006), as it is always possible to continue to explore theory in greater depth. Saturation is a judgment; therefore at some point a decision has to be made to stop when there is enough data to demonstrate recurrence of the central concepts, with no new major properties being revealed.

Dey (1999) contends that rather than establishing categories saturated by data, grounded theorist have categories ‘suggested’ by data, which allows a certain degree of versatility to the grounded theory. In this regards Glaser also considers that modifiability is one of the criteria of a good GT, although it is not basic social processes which change but their variation and relevance (Glaser, 1978).

In this particular study saturation was confirmed through: 1) the recurrence of the core categories (stages) and their components throughout the data; 2) the confirmation of the importance of the three-stage model to participants in the analysis of the last set of data; and 3) the elaboration of the categories (stages) and its properties in the last data set without identifying new ones; therefore the ones established accounted for patterns in the data.

4.5. Ethical Issues in Conducting the Study

This project was formally approved by the Research Ethics Committee at the University of Navarra (Appendix 4.14), recognised by the University of Sheffield’s Research Ethics Committee as having in place sufficiently robust ethics review procedures. A detailed report about the study and its methodological procedures as well as some relevant documents such as the study information sheet, the informed written consent and the interview guide, were provided to the committee to assess the risks, influence, consequences and benefits that the study might have for the participants. Permission to conduct the study in the Memory Unit was also granted by the manager of the centre after examination and discussion of the purpose and procedure of the study.

According to Orb et al. (2001), in any research study, the protection of the human being is essential. All research has potentially harmful effect on participants, so researchers should adopt effective strategies to reduce risks and meet health and safety requirements (Long and Johnson, 2007). In this case, I consciously ensured respect for all participants, by providing sufficient information to support decisions, by understanding and assessing potential problems and changes in circumstances at all times, and by avoiding undue influence in cases of vulnerable participants (Gerrish and Lacey, 2008). Following the research ethics guidance for nurses of the Royal College of Nursing (2009) the following issues were addressed prior the research commence: informed consent; confidentiality; data protection; right to withdraw; potential benefits and potential harm

Ethical Approval and Informed Consent

As has already been mentioned all participants received a detail explanation of the study purpose and its characteristics. In addition written information about the research was provided to both the person with AD and relatives (Appendix 4.2 and 4.3). Both in the information sheet and the written consent form the word ‘Alzheimer´s disease’ was not included. Rather the term ‘memory loss’ was used in order to avoid any harm to any person who did not know or recognize the diagnosis. Likewise, during the interview process the use of ‘Alzheimer`s disease’ was avoided unless the participants chose to use it openly. Few participants (just relatives) used the term to refer to the diagnosis. Most of them used terms such as ‘loss of memory’, ‘forgetfulness episodes’, ‘difficulties in remembering recent events’ and ‘slips and lapses’.

All participants were advised of the possibility of leaving the study whenever they considered appropriate, without detriment to themselves and the care they received. I required their permission to audio-record the interviews, and informed them about the confidentiality of data and the availability of information upon completion of the study.

Written consent was obtained prior to data collection commenced from both the person with AD and the family (Appendix 4.4 and 4.5). Due to the progressive nature of AD disease it was thought that some people with AD may not be able to consent to later interviews but given that they were recruited at an early stage this did not happen. However, in the case that the person with AD had given any indication that he/she wished to leave the study, that person had been withdrawn immediately since the interest of the person (and family members) is assumed to outweigh those of science and society.

Informed consent was seen as a dynamic and ongoing process between me and the participants over the course of the study (Seymour and Ingleton, 1999). Thus continuous agreement to participate in the study took place at different times of the interaction between each participant and me (Beaver et al., 1999; Hellström et al., 2007; Dewing, 2007). This decision was adopted since the choice to freely and voluntarily participate in the study could be compromised due to the disease’s progression and particular family circumstances.

To prepare for the first encounter with families, consideration was given as to how to ensure the informed consent of the person with early stage AD. This should be freely given was considered crucial to the study.

The mere fact of having Alzheimer’s should not necessarily mean the exclusion of a person from taking part in a study. Many people with AD still have sufficient capacity to express their wish to participate in a research study and to provide consent (Hougham, 2005). In this study the people involved were at an early stage of the condition so the issue of competence to make the decision of whether to participate or not was easier to discern than if they had been people in a more advanced stage where competence would have been harder to define.

The capacity the person with AD had to understand the information provided and the degree of voluntariness in taking part in the study were carefully considered throughout the research process.

Written and oral information was personally provided prior to commencing the interviews with the person with AD, both in groups or individually. Attention was given to offer clear and concise information, in an unhurried manner and in constant interaction with the person (through simple questions) to ensure he or she understood the information. I confirmed with them the purpose of the study and asked them to briefly repeat their thoughts at the end of my explanation. The same information was provided at each of the encounters with the person since their ability to retain information over time might be reduced and he or she may forget having consented to the study and not understand what was being asked of them and why. Therefore providing study information and seeking consent at regular intervals throughout the study were the strategies applied. These acted as a ‘reminder’ for people with AD that they were participating in the study and that they were free to withdraw at any time (Alzheimer Europe, 2011).

Sometimes, the presence of other members of the family during the consent procedure may result in relatives making certain decisions on behalf of the person with AD and thus prevent him or her to make a free choice (Agarwal et al., 1996). This issue was addressed by making the consent procedure an individual process for each member of the family. Furthermore, the attitudes people with AD adopted during the interview were constantly monitored to assess their continued willingness to participate.

Data protection, Anonymity and Confidentiality

According to the Data Protection Act (UK Parliament, 1998), all confidential data should be safely stored in a locked cabinet, with authorised access only. Therefore the signed consent forms along with the data obtained in the study were protected in a storage space as well as in a locked file with access restricted to myself. In order to protect the participant’s anonymity, the information gathered during interviews and focus group was stored without any label that identified the participant, and the identity of respondents was replaced by a pseudonym in the analysis process. Furthermore, when disseminating research results, no detailed descriptions that may identify participants were included.

Confidentiality was completely ensured in this study. The information and experiences that participants shared during the interviews (and focus groups) were not disclosed to anyone outside the research nor among relatives of the same family.

Ethics in the Interview

My intention in conducting the interviews was that these were as deep and probing as possible while also being respectful to the interviewees. Ethical dilemmas that may have arisen particularly because of the complexities of entering into private lives of the families and placing their accounts in the public arena were carefully considered. Even though there were no immediate benefits for participants in this study, their participation might help to contribute to an increased knowledge and deeper understanding of the family experience of living with early stage AD. It was my hope that the findings could help to ensure families received quality professional support in the early stages and that this would ultimately improve the quality of life for the whole family.

Although in some cases the depth-interviews resulted in stressful feelings for participants, the opportunity to talk about sensitive and difficult experiences seemed also to have therapeutic benefits. For example, on one occasion one of the participants with AD became emotional and cried while sharing with me a difficult situation for her; she told me how some people at the social club she attended failed to understand her memory loss and sometimes made unpleasant comments about her. This had caused her considerable distress but she had kept it to herself. She did not want to share it with her family to prevent hurting them and because she wanted to continue attending the club despite these incidents. At the end of our encounter she expressed deep appreciation for listening to her story and giving her the opportunity to express the feelings she found difficult to share with her family.

According to Corbin and Morse (2003) *'although illness may be demoralizing, people use storytelling as a way of 're-moralizing'- when life is hard, telling serves a recuperative role in that it enables persons to gain some distance from what is threatening'* (p. 346). Some participants openly acknowledged the positive dimension of sharing their experiences and the opportunity to be heard. For some it was a form of 'relief'; for others it meant a time for 'reflection' on their particular situation. Undoubtedly this was achieved through a trusting and respectful relationship between participants and me.

I worked on establishing familiarity, trust and rapport to tune into the participant's language, communication, skills, and become aware of the knowledge and willingness to share the experience each member of the family had. Since some sensitive issues were discussed during the encounters, it was crucial to create a suitable atmosphere to enable participants to share their experiences freely, without coercion or pressure, giving them time to recuperate, guiding the interview but without directing and forcing answers.

Establishing rapport and confidence during the research process required time and dedication but provided richness to the data gathered. Common, but attentive, strategies such as periodic phone calls and Christmas cards allowed me to become familiar to participants and established a trusting relationship that promoted fluent and relax conversations with the families, particularly during the second and third encounters. Investing time in building such a relationship enhanced the research process and facilitated the collection of meaningful and significant experiences.

Confidentiality of the interviewees was protected at all time. Furthermore, I made sure that transcribed texts were loyal to the interviewee’s oral testimony. I shared the data with interviewees in order to allow they have a say in how their statements were interpreted. Linked to this I reported knowledge that was as secured and verified as possible.

4.6 Ensuring Rigour of the Study

Judging the quality and rigour of a qualitative study is still a hotly debated area with many differing and sometimes conflicting frameworks having been proposed. Research studies need to be evaluated according to criteria suitable for the paradigm to which they belong. Thus the quality criteria used to evaluate quantitative research (reliability, objectivity and validity) cannot be necessarily used to evaluate qualitative studies since they have different approaches and objectives. In judging the rigour of the present study I decided to apply the main dimensions of the quality criteria for GT as described by Charmaz (2006), these being credibility, originality, resonance and usefulness. To explore these Charmaz outlined a series of questions that need to be asked of the resultant GT (Charmaz, 2006, p. 182):

Credibility

- Has your research achieved intimate familiarity with the setting or topic?

- Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.

- Have you made systematic comparisons between observations and between categories?

- Do the categories cover a wide range of empirical observations?

- Are there strong logical links between the gathered data and your argument and analysis?

- Has your research provided enough evidence for your claims to allow the reader to form an independent assessment –and agree with your claims?

Originality

- Are your categories fresh? Do they offer new insights?

- Does your analysis provide a new conceptual rendering of the data?

- What is the social and theoretical significance of this work?

- How does your GT challenge, extend, or refine current ideas, concepts, and practices?

Resonance

- Do the categories portray the fullness of the studied experience?

- Have you revealed both luminal and unstable taken-for-granted meanings?

- Have you drawn links between larger collectives or institutions and individual lives, when the data so indicate?

- Does your GT make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?

Usefulness

- Does your analysis offer interpretations that people can use in their everyday worlds?
- Do your analytic categories suggest any generic processes?
- If so, have you examined these generic processes for tacit implications?
- Can the analysis spark further research in other substantive areas?
- How does your work contribute to knowledge? How does it contribute to making a better world?

Answers to these questions will be provided later in Chapter 7.

Summary

This chapter has provided the rationale for using a constructivist GT approach to achieve a better understanding of the family processes involve in living with early stage AD. The reasons why the qualitative paradigm and specifically GT were especially suited for that purpose have been explored and the specific study design, sampling technique, data collection procedures, analytical methods and quality assessment criteria of the study have been detailed, together with ethical considerations. The following two chapters present the results of the study.

CHAPTER 5

FAMILY DYNAMICS AND LIVING WITH AD: SEVEN FAMILY CASE STUDIES

Introduction

The overall purpose of the study was to explore the processes that take place in the family while living with early stage Alzheimer Disease (AD) of an older family member. Specifically the study aimed to understand how this experience affected the structure, interactions and dynamics of the family unit; and to comprehend what living with AD meant to the person and the others involved and, how this was influenced by their values, beliefs and expectations in general and those related to the condition in particular.

This and the following chapter presents the main findings of the study based on the experiences that families shared during the successive series of interviews and the focus groups conducted during the final stage of the research.

This chapter begins by describing the study sample before moving on to a case study presentation of each of the seven family participants involved in the study. These family case studies provide an account of the circumstances and context of the family units to provide a background to the three stage temporal model of the subjective experience of living with early stage AD that is considered in chapter 6. The present chapter concludes with an overview and reflection on the family cases and the development of a typology of family dynamics.

5.1 Socio-demographic Characteristics of Study Participants

A total of seven families living with early stage AD were recruited from the Memory Unit of the SFJ. Psycogeriatric Centre in Navarra (Spain). Characteristics of people with AD involved in the study varied by gender, age, socioeconomic status, housing, cognitive assessment and time from diagnosis confirmation. Relative’s characteristics were also diverse, with families having different structures and relationships.

As noted in the previous chapter a total of 26 interviews were undertaken involving seven people with AD and fifteen relatives. Additionally three focus groups were conducted in the final stage of the study which included fourteen relatives of people with middle-advanced AD.

Among the seven people with AD included in the study there were five females and two males. Their ages ranged from 72 to 85 years. Educational level also varied; one of the participants attended college, another two had high school education while the remaining four had elementary education. At baseline three people with AD lived alone at home while the other four lived with a relative (two with their husbands, one with his wife and other one with her daughter and son-in-law). However, during the course of study some housing circumstances altered. Two people continued living alone while the rest lived with a relative (one with her husband, one with his wife, one with his daughters and two with her daughters and sons in law).

MMSE scores ranged from 18 to 22 indicating mild cognitive impairment. The time elapsed since receiving diagnostic confirmation also differed from four to more than ten months, although most participants stated that the ‘memory loss’ episodes had begun well in advance of receiving the diagnosis (see Appendix 5.1).

The relatives sample consisted of thirteen females (one wife, one goddaughter and eleven daughters) and two males (one son and a husband). Ages ranged from 38 to 79 years old. Six relatives had higher education while the other nine had primary studies. In terms of occupation, three were retired, one was a housewife, and five worked full-time, although two of them were on leave of absence over the course of the study; the six remaining were unemployed (see Appendix 5.2). Information about the whole family unit, which involved other significant family members, is provided below when the family case studies are presented.

In the final stage of the study fourteen relatives of people with AD agreed to participate in three focus groups. Of those twelve were daughters aged between 33 and 57 years, and two husbands aged 65 and 75. Ten of them lived in the city while the rest lived in a rural area of the region. The number of years living with AD ranged from three to eight years (see Appendix 5.3).

5.2 Family Case Studies

During the analysis of data I realized the critical role that an understanding of prior interaction and dynamics among the family participants played in developing a full understanding of the AD experience. Past relationships and interactions proved to have a strong influence on the responses of families to the presence of the condition and the motivations and expectations they had regarding care. Thus, gaining a complete and thorough comprehension of the AD and care experience required a consideration of the nature, type and quality of both past and present interactions in the family unit.

As the data analysis progressed and my theoretical sensitivity increased, it became apparent that in the family experiences the following elements were significant:

- Prior family interactions and the interpersonal dynamics of the members of the family before the onset of AD.
- The values and associated behaviours that the families demonstrated.
- The resources, both internal and external, that the family had.
- Their vision of the future.
- Family interactions and interpersonal dynamics after the onset of AD.

Whilst the above factors played a part for all families each family brought its unique history (biography) which was central to understanding how living with AD impacted on the family. Therefore what follows is a detailed biography of each family which considers their key characteristics.

For the sake of consistency, each family case study is presented using a similar format. Firstly a brief description of the family structure is provided, identifying the members who took an active part in the study and those who were significant to the care experience, although they did not directly participate in the study. Secondly how the condition (memory loss) was regarded and significant experiences for the family surrounding the diagnosis are described. Thirdly, family dynamics, with particular reference to the prior family interactions and their influence on the way the family responded to the presence of AD, is introduced. Each case study addresses the elements outlined above but the emphasis given varies according to each family. To conclude a brief reflection on the dominant family work type is provided (see Appendix 5.4 for a brief summary of each family case study).

The family case studies are presented according to the order each family was recruited into the study, giving a sense of the development of the research. Following participants' agreement, all names have been anonymised by use of pseudonyms to protect the identities of the participating families.

5.2.1 The Armendariz Family

The Armendariz family comprised a husband and wife, Abel and Anne, and their two children Adela and Adrian. Only the couple and their daughter Adela took part in the study. Adrian, the son, lived abroad, even though he played a significant role in the family caring. Abel was diagnosed with AD at 73 years of age, and lived with his wife Anne. At the point of entry to the study they had been married for 50 years. When Abel and Anne entered the study they were 73 and 75 respectively; and their children, Adela and Adrian, aged 42 and 41.

The couple lived in a large flat close to the city centre. Adela, their daughter, lived quite close to them and provided considerable support for her parents in this situation. Adela was married and had two little children (aged 7 and 2 respectively). She visited her parents every day, accompanied by her children, who were the *'joy of the house'* according to Anne. At study entry Adela was unemployed, although she was working on an upcoming project with her husband. Adrian, the son, lived in the US and travelled continuously due to his job. Even though he lived far away he showed a profound concern about his parents' situation. Abel pointed this out during our first encounter, when he actively recognized that Adrian, his son, called home more than twice a day. It seemed that the frequency of his calls had increased in the past few months, coinciding with the confirmation of Abel's diagnosis.

AD Awareness and Diagnosis

There was no family history of AD or any other type of dementia as far as the participants could recall. Abel was diagnosed with AD in November 2011, though the family started noticing some *'anomalies'* in Abel's behaviours at the beginning of that year. Given this, they decided to consult Adrian's friend who worked as a private neurologist for his opinion. Consequently, although the family was able to receive assistance from the public health care system, Abel's AD case was managed from the neurological unit of a private hospital in Navarra. Two months after confirming the diagnosis Abel started attending the 4-month memory unit programme for cognitive training at the SFJ Psichogeriatric Centre, where I met the family for the first time to provide them with detailed information about the study.

During our first encounter at the couples' house I ascertained that Abel was not completely 'aware' of the memory loss and related difficulties he had, and played them down. Despite noticing that he had some *'memory lapses'* (as he referred to them) he tried to justify these by looking for external factors to provide a logical explanation for the episodes. For example, whilst the family talked about Abel's recent poor driving, one of the early signs that the family noticed, Abel actively denied this it by arguing that driving was not as safe as it had been and he insisted that the fault did not lie with him but with poor standards generally:

> ***Abel:*** *My situation is not extreme*
> ***Adela:*** *The thing is that now he has some distractions while driving that he did not have before.*
> ***Abel:*** *Well, but… you should recognize that driving is not as safe as it was before, is it?*
> ***Adela:*** *Yeah*

> **Abel:** *I really do it (*driving) *perfectly*

Anne’s reaction to her husband´s ‘memory loss’ was both protective and practical. Consequently, she would manage day-to-day life by working around her husband’s needs and minimising any problems that she thought he might have by planning in advance. For example, she now rose before he husband and ensured that what he needed for breakfast was readily at hand. This meant that Abel could prepare his own breakfast but did not have to go searching for what he needed. This both maintained his sense of independence and reduced the possibility of failure. During our first (group) encounter Anne did not fully share her feelings; she tended to downplay her thoughts about her new situation and even avoided any real acknowledgment in front of her daughter and husband. This led me to suggest to Anne the possibility of having an individual encounter so that she could verbalize her experience more freely. She completely agreed with my suggestion and during our individual encounter she told me that she preferred to talk to me in private as she felt more relaxed sharing her feelings if her husband and children were not present.

Anne constantly tried to normalize her husband’s situation and did not want it widely known. For this reason it was agreed within the family that the diagnosis would only be shared with close members of the family.

> **Anne:** *For example with my sisters…-one of them lives in Barcelona, the other one is in Burgos, other lives here and the last one is in Madrid-…Well, I have not told them what he really has.*
> **Nuria:** *What are the reasons for that decision, Anne?*
> **Anne:** *When they call home they often ask me: ‘How is Abel?’ I tend to tell them: ‘Look, you know he has little distractions and this stuff so we both go to the memory unit…’ You know what I mean, Nuria? Because you know what, they may treat him as if he were... I rather prefer to see if together, doing everything as normal as possible… I do not know if I am right or wrong.*
> **Nuria:** *Well, it’s natural that…*
> **Anne:** *You know what? I just want he acts as normal as possible.*

Anne did not want her husband to feel like '*a sick person'* as she put it. Therefore rather than overtly watch what Abel was doing she kept a subtle eye on his activities and tried to keep things as normal as possible. In her view she was protecting him from the full impact of the condition. She also did not want to see her husband viewed as being 'lost' to AD as she had noticed other people with a similar condition had become. For example, on one occasion during our second encounter she talked about a neighbour who suffered advance stage AD. She referred to him as *'being lost' (do not have remedy, you're hopeless)*, and expressed feeling shame and regret when she looked at him.

As the following quote illustrates Anne did not want to think about her husband being viewed in this way by others and being treated differently because of this. Rather she wanted Abel to be seen as a competent person by those around him:

> ***Anne:*** *For example, my neighbours often say to me: 'I see how well you take care of Abel!' I do not know if they have noticed something to say that. 'You are always with Abel'… Then, I usually reply to them by saying: 'He is who comes with me', making them believe that I am not taking care of him but he is who take care of me. As If I were who'd need company, you know what I mean?*
> ***Nuria:*** *Anne, are you afraid people treat Abel in a different way?*
> ***Anne:*** *That'd make me suffer a lot...*

Family Dynamics

Relationships within the family had always been close and strong. This was evidenced by the frequent examples the family provided about the difficulties they experienced throughout life, for instance, the economic hardship they suffered and the efforts they had made to provide a good education to their children. But despite these, they always faced things together as a family. Additionally during the interviews there were numerous displays of affection and trust, such as holding each other's hands, and praising each other's behaviours. The Armendariz defined themselves as a close family, with a well-founded sense of family unity that was inspired by the religious beliefs (Christian faith) that all its members shared. Adela acknowledged that the diagnosis of AD had helped everyone to preserve and strengthen the belief they have of the family as being a priority in life. This strong sense of being a family was a major resource that helped to shape how the family lived with AD. It was clear this sense of family that turned out to be a strong element that encouraged its members to live with AD as long as possible.

The values of the family held revolved around providing care and support to its members. Throughout their life Abel and Anne had always directed their efforts to bringing up and assisting their children and this pattern was now being maintained over time and across generations:

> ***Anne:*** *We've fought for them. We`ve always been fighting for them.*
> ***Abel:*** *Always, always! We have always been caring for them.*
> ***Adela:*** *Yeah, yeah. Of course!*
> ***Abel:*** *I gave them everything they need to study and such stuff.*
> ***Anne:*** *They have always done what they have wanted.*
> ***Abel:*** *Whatever they have been able to do is what they have done*
> ***Anne:*** *You know what? We have… our children are our best capital (she hit the table to emphasize what she said)*
> ***Adela:*** *To be honest, that is something I have always seen at home and now I hardly try to transmit to my own family, you understand? I've lived that in first person so now I want it too.*

Family caring was motivated by the solid emotional ties that existed among its members. Caring was understood as a shared responsibility helping family members to work together to cope with the condition and the challenges that caring might bring for them, as the following quote suggests:

> ***Anne:*** *They (my children) are always taking care of us. Adela is all the time asking: 'Mom, are you alright?' And we see each other every single day. And the other one, Adrian, he cares for us although he is many kilometres away. He always keeps an eye on us (…) that's what I've told you that we are 'all at once' (laughs) to make this easier.*

Roles and responsibilities within the family were quite clearly defined. Abel had always been the provider while Anne was in charge of raising their children and tending to the house. Adela described this as follows: '*My father had to travel constantly due to his job therefore my mother was the one at home. She has always worked to promote family unity'.*

One of the major responsibilities of Abel was being in charge of the family finances. However, following the onset of AD Anne was increasingly assuming this task, even though Adela assisted her with it. This change did not entail major stress in the family as Abel progressively lost initiative and interest in this task therefore facilitating the shift in family responsibilities.

Albeit caring was a shared experience, Anne assumed the vast majority of her husband's care. She conveyed her desire to *'bear the burden of care alone',* consistent with her protective attitude, both for Abel and her wider family.

> ***Anne:*** *I'd prefer to bear the burden of the situation alone and no one get hurt. With this is everything said, isn't it? That whatever happen just happen to me and ... and the others…*
> ***Adela****: but this is not like that at all!*

This protective approach was not only directed towards her husband but extended to the whole family group. This was evidenced by episodes such as the decision Anne made not to tell her son they were participating in the study because she did not want this to cause alarm and concern to him. She made this quite clear to me at the outset. In a similar manner Anne extended this protective attitude toward Adela. Anne wanted to bother her daughter as little as possible. She strongly believed that Adela had her own life and that asking her for support might make extra-work and stress for her:

> ***Anne:*** *You know what? I know that this situation is something to deal all together, but Adela is really stressed, she has her own work, her husband, she is... You know? They need to work on their own life and everything. She has two children, we help her when we can... caring for the children who are..., especially the boy, the joyful of the house.*

> *So I want to bother her as little as possible. Nuria, I see her a bit nervous, with her work, with her kids... Then I say to myself: 'I cannot pour over her more things!'*

Anne's efforts directed at having control of everything and protecting Abel and the rest of the family from suffering, despite being well intentioned, created an intense *'internal stress and nervousness'* in her. Adela, her daughter, voiced a profound concern about this situation. She noticed that Anne suffered but despite this she did not share her feelings and concerns with the rest of the family:

> ***Adela:*** *Sometimes she talks behind closed doors and I often say to her: 'tell me, share with me…' I think this way at least she could vent and such. But she is not able to share her feelings with us, you understand?*

This reluctance Anne had to sharing her own feelings with the rest of the family reinforced the belief by Adela's that her mother was the one who really needed support in this situation. She suggested her mother should have a contact person, someone who she could talk openly to and share her suffering with. Anne, unknown to Adela, reinforced this view when she confided to me that she felt more comfortable sharing her experiences, feelings and thoughts with someone outside the family.

As well as strong family values the Armendariz were Catholic and drew on their own faith to attach meaning to the disease and the caring experience. This was highlighted by Anne who shared with me the moment she and her husband received the Extreme Unction whilst participating in the study and they firmly believed that this provided them with the support needed to deal with their suffering. According to Anne faith was central to their support and made them *'feel relieved'*. This spiritual sustenance was also revealed when talking about the future. I asked the family about their vision for future to obtain an idea about their shared hopes, plans and expectations. Interestingly their reflections focused on the present day rather than the future and they adopted a '*living day-to-day'* approach. This proved to be based primarily on their religious beliefs as the family considered that God gave them each day as it came, thus they had to cope with this as best as they could.

Unfortunately Abel’s condition deteriorated towards the end of the study. Therefore when I contact the family (Anne) to consider the possibility of conducting a third interview I found this was not possible. During our phone conversation I perceived that Anne was overwhelmed by the deterioration in Abel’s health status and whilst she wanted to continue to care for her husband she did not want to talk about it, possibly because this might confront her with the reality of her deteriorating situation. However she stated that she had enjoyed taking part in the study and hoped that her contribution had been of help.

Reflections

The dominant family dynamic here was one primarily of closeness in which emotional bonds were and remained strong. Members of the family shared a deep commitment to the family as they provided support, help, and time for one another. Decisions regarding care tended to be made with the whole family in mind, although the protective attitude that some of its members (especially Anne, the wife) developed toward Abel, the person with AD, left him out of care decisions. Abel was in many ways not fully aware of the support that his family were providing to him.

Appreciation of each other, deep religious beliefs and feelings of belonging were central to the family during their challenging circumstances. Despite their difficulties there was a high level of affective involvement in caregiving which contributed to the family being able to search for positive outcomes on a daily basis rather than looking too far into the future.

5.2.2 The Blasco Family

The Blasco family care was principally made up of four individuals; mother Barbara, along with her three daughters Bea, Beatriz, and Blanca, the youngest one. All of them took active part in the study.

Barbara was 74 years old at entry to the study. She was orphaned and had no contact with any relative other than her daughters. Barbara had been widowed since 2002. Prior to this she had cared for her husband, who was in a wheelchair for many years; therefore his death had a major impact on Barbara’s life as she felt that her life had lost its purpose since then. Moreover she attributed her current health status to the suffering she had experienced since her husband’s death.

Barbara was diagnosed with AD in March 2011. She remained independent and living alone while participating in the study. Among other things Barbara really enjoyed going for a walk with a kitten and a puppy she had. This was an important part of her daily routine. In addition to the three daughters involved in the study, Barbara had two other children, one of whom died shortly after birth and the other had suffered a natural abortion. Her three daughters, Bea, Beatriz and Blanca, lived in different and quite distant districts from Barbara’s house, although these were well connected via public transport.

Bea was 47 years old. She was married and had two boys (aged 26 and 27) who were not really involved with Barbara’s situation. Bea had been married and had left the family home when she was fairly young. Relationships with Barbara had always been distant and cold. Beatriz meanwhile was 43 years old. She was married at the entry of the study and had two little children. However she and her husband parted during the study. Her relationship with Barbara was almost nonexistent until the onset of AD. Beatriz considered her mother had a dominant nature and she felt that Barbara had always controlled her life. For that reason once she left home she decided to break off their relationship. Blanca, the youngest one, was 38 years old. Although relationships with Barbara had not been entirely trouble-free she was the closest to her. Blanca was married and had a girl aged 10 year, who maintained a pleasant relationship with her grandmother.

AD Awareness and Diagnosis

Barbara was diagnosed with AD in 2011. However, she and her three daughters deemed the death of Barbara’s husband (in 2002) to be the trigger for changes in

Barbara’s behaviours, mood and lifestyle. These changes had increased over the past three years. According to Barbara’s daughters their mother became more suspicious and distrustful than usual. Although her character had always been rather difficult this had exacerbated noticeably over recent times.

The continuation and worsening of Barabara’s suspicious behaviour over time was the trigger that led her daughters to seek medical assessment and confirmation. Unfortunately for the family the response from the GP, over numerous visits was not to take steps to confirm a clinical diagnosis, and to provide the necessary support that the family required at that time, but rather to attribute the changes to ageing, as the following quote illustrates:

> ***Blanca:*** *(...) you know what, I told my GP: ‘I've been coming here for 5 years to discuss the same issue; what have you done? You have not given me any guideline neither you have told me where I should go… tell me! Please, do not tell me that my mother is getting old and that´s it, because that’s wrong. Tell me something!! Sometimes, this is an overload.*

Initially the GP’s judgements on Barbara’s health status focussed on depression and the ageing process. This caused a struggle with the family, as her daughters strongly believed their mother was medically unwell. As Barbara’s behaviours repeated over time, her daughters insisted on the need to reassess their mother’s health status. Finally after an extended period (years) of seeking for a definite/accurate diagnosis, Barbara was referred to the neurologist who confirmed the AD diagnosis. A few months later she began to attend the memory unit programme for cognitive training at the SFJ Psychogeriatric Centre. This was something that was positively valued by Barbara.

The period surrounding diagnosis was a traumatic one for this family. The lack of interest from the GP caused resentment and discomfort within the family, and even created an 'unfriendly' relationship between the family (especially daughters) and the professional health-care services that extended over the care experience. Difficult encounters with healthcare professionals occurred repeatedly, increasing the poor perception the family had about formal support at this stage. The following quote provides an example of these encounters:

> ***Beatriz:*** *One day the nurse told me (…) 'have you seen how your mother is dressed up?'; 'Oh shit…, what am I suppose to do? Taking her and dressing her by force?' I perfectly knew how my mother was dressed up. That day was freezing; we were around 6 or 7 degrees below zero and my mother just wore a thin jacket.*
> ***Blanca:*** *It was one of these days that weather was so cold...*
> ***Beatriz:*** *Of course I saw how she was dress up. But what did you expect? She did not want to wear... And to top, the nurse told me if I had not realized how she was dressed up... 'Of course I realize it. Do you think I'm stupid? Obviously I am not'*
> ***Blanca:*** *We're constantly saying to her: 'mum please, change your clothes, and take these ones'... She has lot of clothes, OMG! She has four closets full of...*
> ***Beatriz:*** *But for that nurse it seemed that we did not care about. She (Barbara) ignores us completely. There is no way, there is no way to take her home and convince her to change her clothes. No, there is no way, because she causes such scenes...*

One of the toughest challenges that the daughters faced with at the onset of AD was that of dealing with Barbara's challenging behaviours (which had contributed over time to the complex relationship between them). This caused profound distress and made family interactions hard to manage. The above episode proved to be significant for the daughters who, far from receiving support on how to handle the complex experience, felt judged by professionals.

> ***Bea:*** *the worst thing is that you perceive they (professionals) do not care about you. They just say to you basic things you already know; you do not need to be a specialist: 'Please, I have no studies but I know it'. That's the thing that largely demoralizes you. This is not about my mother has a disease that has no cure but the way they (do not) help you to approach to it, the way they help you to live with it.*

Barbara was aware of the difficulties she experienced though she did not openly acknowledge the diagnosis. During our different encounters Barbara discussed the changes she noticed and the impact these had on her daily life. Nevertheless at the start of the study the complex relationship Barbara had with her daughters proved to be more intrusive in her experience than the condition itself. Barbara's first accounts were largely focused on the fraught mother-daughters relationship.

> ***Barbara:*** *(…) Perhaps I am going to say something and they (my daughters) suddenly say 'shut up!' This has always been the same, I cannot, I can talk about nothing with them, you understand? They have quite a strong temperament. Then I have to shut up. Sometimes when I am with them they say to me: 'shut up mom'; 'Well girls, I will shut up'. I feel like a fool. When I am with them I feel I cannot talk, I can say nothing.*

In subsequent encounters a slight improvement in family relationships was observed. As a consequence Barbara's discourse was focused on the impact of memory loss on her life and that of her family, rather than family conflicts. She also felt that her daughters cared more about her than before, albeit family relationships remained difficult. This tension was evident as Barbara often insisted that I did not share her accounts with her daughters.

> ***Barbara:*** *Well I feel I have poor, poor memory. I can no longer do anything like I did before.*
> ***Nuria:*** *what types of things you refer to?*
> ***Barbara:*** *Well, having walks, going out... I've forgotten where the shops are and I cannot go alone anywhere. I do not know where the stores are, where this store is. Neither this nor that! Nothing! I have forgotten everything. I have forgotten everything! (…) Thanks to my daughters that tell me 'you know that tomorrow we have to go to the doctor', 'you know this, and you know that'. Thanks them! Before, they did not care so much about me; but now, now they come with me a lot. Don't tell them please! Don't tell them please!*
> ***Nuria:*** *Don't worry about that Barbara.*

> **Barbara:** *Now they do. They are constantly caring about everything, doctor's appointments and everything.*

Family Dynamics

Relationships in this family had always been difficult, with long periods in which there was no contact between them. This was openly acknowledged by the family when they decided to take part in the study and wanted to be interviewed separately. Because of this long history there were few shared moments of family togetherness. There were however some differences.

Bea and Blanca had always maintained friendlier relationships with her mother as noted by Bea during our first encounter: *'my mother has always quarrelled more with my sister Beatriz than with us'.* The type of prior relationship each daughter had with their mother influenced the manner and the extent to which each was involved in the caregiving experience.

Until the onset of Barbara's AD, each member of the family maintained quite independent lives. They only had sporadic contact when urgently needed, for instance, the time Blanca needed surgery due to a back injury. However, as a result of the deteriorating health status of Barbara, her daughters began meeting each other to discuss and confirm about was happening. This increasing contact between them led to slightly improved family relationships.

> **Blanca:** *Well, this is not just the only reason but this has influenced it. Because there are periods in which we see each other more frequently, we talk every day…*
> **Bea:** *Yeah. We see each other more than...*
> **Blanca:** *Now we get together more often*

Initially all the three daughters seemed to be involved in the care experience, although different motivations were identified when they were asked for the reasons that had led them to take care of her mother:

> **Beatriz:** *Because she is my mother and I have to do it.*
> **Blanca**: *Dammit! Because we love her*

> **Bea:** *We want she feels good; living with us, living in a nursing home... wherever she was. She has suffered a lot during her life so at least now, the last times of her life, she should have a good time. Under whatever circumstances but that she is alright. If she wants to be alone, with my sisters or with me… but that she feels alright (...)*
> **Beatriz**: *Our relationships have not been quite easy but we are not leaving her like...*
> **Blanca:** *(We are not) throwing her...*
> **Bea:** *We are not getting to such extreme!*

As is suggested in the above quotation despite her daughters not having a profound sense of commitment and affection for their mother, they felt an obligation to support her. What appeared to count the most was a sense of duty (‘*she is our mother*’ ‘*we´re not leaving her…*’), which seemed to be linked to the social conviction that exists within Spanish family culture that children must take care of their parents. This duty-driven attitude towards care was rooted in their prior poor relationships and disagreements had eroded any lasting family bonds. For these reasons family caregiving was largely considered a stressful experience, in which the daughters felt trapped:

> **Blanca:** *This is how I feel. This is determining my life. For example now that I want to go to my village to spend my Easter holydays… I’ve been thinking: ‘if we’re going to the village, how long time we’ll stay there? If I have to be with her (my mother)…’ Because if something comes up and she (her sister) cannot help her with it because she is with her kids… Besides, you feel a little, you feel almost guilty, don’t you? Like If you were away and then you left her (my mother) here. Also, if we have to do some paperwork and you cannot go and then my sister has to go, you feel a little wicked, as if I…*
> **Beatriz:** *Yeah, ‘I´ve give it to her’*
> **Blanca:** *(…) I really feel overwhelmed, overwhelmed! Yes, because you talk and talk and talk and I do not get any solution. Then I am overwhelmed. This is determining my life. I’ve had to stop doing things for my house. And thanks God that I am not working. If I would*

> *have to work I do not know what might happen here! And who is responsible of this? It´s our responsibility, of course it is. But none help us! People ask for more support for older people in the TV… But, when you need help, they do know nothing.*

The daughters seemed to regard caregiving as a factor dominating their lives, preventing them from doing other things. The difficulties that overshadowed the family experience led the daughters to feel lost and living in fear that things could only get worse.

This was certainly the case with Blanca who did not get involved in care activities. Furthermore, Beatriz's relationship with her mother deteriorated to the point of Bea and Blanca having to intervene. They ultimately decided to break relationship with their sister and took legal action to keep Beatriz away from her mother.

This event, despite being very painful actually improved relationships among the rest of the family. Barbara became closer to her daughter Blanca and she began to spend increasing periods of time with her and her family. At the same time Bea became the principal support for her sister Blanca, and helped her in caring activities, although she kept the largely distance relationship that had always existed with her mother.

Reflections

The dominant family dynamic here was one of conflict and disengagement. Emotional bonding had been eroded by frequent disputes and relationships were poor. As a consequence family members regarded the caring experience as a duty, which in turn, made it more difficult to them find satisfactions from care.

Disagreement and rupture were prominent dynamics in this family. Family members tended to undermine each other and engaged in one-upmanship, especially the second daughter. However, when family breakdown eventually occurred and Beatriz separated from family, a more relaxed environment emerged among the rest of members resulting in a closer family dynamic that changed the family caregiving experience to the better.

5.2.3 The Cervera Family

The Cervera family comprised a couple, Carmen (the person with AD, aged 77) and her husband Carlos (aged 79), and their four daughters Camila the youngest one (aged 43), Cecilia (aged 47), Carla (aged 50) and the oldest one Carolina (aged 52). Except for Carolina, everyone actively participated in the study. The relationship that Carolina had with her parents was more distant than the relationships her sisters had with them, therefore the level of involvement in the AD experience varied substantially.

The couple had also had a son, who died in a traffic accident when he was 19 years old. This experience had a profound impact on Carmen's life, who admitted not having overcome this tragic experience. Interestingly, one of the earliest changes that the family noticed in Carmen's behaviours was the constant reference she made to her son and issues related to him. Explicitly, during our first interview the family described an episode at the beginning of their experience with AD in which Carmen insistent that she had to pick up her son from school. This was a decisive event for them that led them to seek medical assistance.

Carmen was diagnosed with AD at 77 years of age, and lived with her husband Carlos, who, at the point of entry to the study, she had been married to for 51 years. The couple had always lived in a large house in the countryside. However after confirming Carmen's diagnosis they decided to move to a flat in the city, close to their three daughters. This decision was made following agreement by all the family members involved. At that time both the couple and their daughters considered this option was the most suitable for everyone's wellbeing. However whilst they live close by everyone still sought to maintain their own lives as far as possible, keeping their privacy and own routines.

Camila, the youngest daughter, was married and had two children, a boy aged 11 and a girl aged 12. The girl had a close relationship with her grandparents and she was especially touched by her grandmother's disease. This was clear when Camila recounted an episode that occurred to her daughter at school:

> ***Camila:*** *Few days ago my daughter made a drawing at school…. her teacher asked them: 'Well, now I would like you express your feeling about your family and your life', in order she knew a little bit about this. And…, mom I have to bring it to you, because she created a drawing with lot of colours, finger painted… and she also drew four black circles on each corner of the picture. The teacher got surprised when saw that so she asked my daughter: 'you have lot of colours but what about those black circles?' My daughter said: 'Yeah, these are the worries I have'. The teacher asked her to put in words and she wrote: Red and yellow colours are my happiness; black circles represent my grandmother's disease.*
> ***Carmen:*** *My god! What you think about? (…)*
> ***Camila:*** *They are always together. Our children spend lot of time with our parents… however she did not tell me that. The teacher asked her: 'Have you talked about this with your mother' and she replied to her: 'No, no, because I see my mother is not alright'. So true! Because when we received the confirmation, I did not digest it, I was really worried and always thinking about it. Now I am better.*

The close relationships that members of the family maintained meant that the emotional impact of AD was not felt only by the daughters but also by her grandchildren.

Cecilia was also married and had a teenager girl aged 13. During the first year that the couple lived in the city Cecilia and her sister Camila went to visit their parents every morning. They mainly helped their father with the housework and Calista's care activity. Cecilia and Camila were unemployed at this time and this allowed them additional time to lend a hand to their parents.

Carla, the second daughter, was also married and had two adult children. Though unlike her sisters she had a full-time job at the hospital, but she still provided care to her parents. During the month after diagnosis Carla went to visit her parents every afternoon and helped them to become familiar with the neighbourhood by meeting new people. Nevertheless the unexpected death of Carmen's husband Carlos, almost a year after Carmen's diagnosis, led Carla to ask for a leave of absence and she devoted her time entirely caring for her mother. Carla had previously taken charge in the family when difficult situations had arisen (such as her brother's death). She seemed to have the capacity to overcome difficulties, take control of situations and provided support to the rest of the family.

AD Awareness and Diagnosis

Carmen's oldest brother also had AD. He was in an advanced stage and had received nursing-home care for about two years. Even though Carmen knew her brother's diagnosis and visited him in the centre she displayed a complete conviction that she did not have her brother's disease.

Carmen denied having AD despite her daughters Carla and Cecilia openly sharing the diagnosis with her. During one of our encounters Carla explained to Carmen what happened to her cognitive function. She told her that the disease she suffered from was called Alzheimer and it was, in her own words, '*the disease of the memory'.* Carmen's reaction was defensive although she acknowledged that something had happened to her.

During the succeeding encounters I had with the family I noticed that Carmen assumed a passive role, she knew she had memory loss but she understood it as a consequence of getting older. Carmen was delighted to be receiving her daughter's care since for her (and the rest of the family) care was considered a family commitment, and a filial responsibility. This notion of caregiving was evident in some of the Carmen's interviews:

> ***Carmen:*** *She (Carla) is a very hardworking person. She left her job just to take care of me.*
> ***Nuria:*** *and what do you think about that?*
> ***Carmen:*** *Well… listen, on one hand I consider this is right because I am her mother!*

This vision of caregiving was also voiced by Carla who gave an account of what caring for her mother implied to her:

> **Carla:** *Her disease? You can handle it! You have to take off your life. I mean, of course it involves. I mean, it involves a lot. You are with her all day, by and for her, you live only for her.*
> **Carmen:** *I've also had all the days for you when you were born… until you got married!*

Apparently the whole family considered caregiving as a family commitment. Therefore the daughters' care was largely motivated by a sense of devotion and gratitude toward their parents, who had cared for, educated and support them throughout life.

> **Carla***: This situation is the same that the one in which my father suffered from cancer and I decided to take care of him. I mean, it (caring) has always being my role within the family. The same situation when my brother died. Then, I have always had to handle these situations. Because my older sister, she has always been in the background, you know what I mean? I mean, she is present but at the same time she is not (…). And I do not mind because my parents have always helped me when I've needed it, you know? Then, I do not mind. All I would have wished is having more money to live with them in a big house!*

In sharp contrast to the Blasco family, the caring activity of this family was less duty-driven and was underpinned by personal affection and attachment. This more closely reflects the parent-children relationship that is widely promoted in Spanish culture and is seen as part of family intergenerational solidarity.

Family Dynamics

Relationships for this family had always been close. Supporting each other was both a shared expectation and a responsibility within the family. The couple's life, especially from Carmen's perspective, was largely directed at taking care of their children. This value continued over time and across the generations as the last interview with Cecilia suggests:

> **Carmen:** *To me, the most important thing in life has been taking care of my children, giving them everything I've could, being with them, playing with them, making them laughing*
>
> **Cecilia:** *Everything has its time... I mean, now it's time we... they need us.*

For the first year after confirming the AD diagnosis this family was fairly well organized. All the members were close to each other and willing to collaborate and get involved in the family care experience. Initially Carlos was supposed to be the main caregiver although he received considerable support from his daughters. They assisted him with the housework and Carmen's care since he had never done such things.

Nevertheless his unexpected death, during summer 2012, caused major changes in the dynamics of the family. Carlos died from an incurable cancer that only allowed him to live three months after the diagnosis. This was a turning point in the life of this family since this event impacted on the structure, function and interactions of the family, consequently affecting the present caregiving experience. Carlos was the unifying element in the family. All his efforts were directed to keep the family together as his daughters stated. The emotional impact of his death affected family relationships for the worse, and some distancing among members took place. Henceforth disagreements that arose within the family with respect to Carmen's care did not get resolved but aggravated and fuelled conflict among family members.

Emotional ties became closer between Carla and Cecilia, who supported each other in grieving the loss of their father and providing their mother's care. Interactions with Carolina, the oldest daughter, remained distant whereas relationships with Camila, the youngest sister, deteriorated till reaching a complete rupture. Camila, the youngest daughter, had always relied on her parents. Unlike her sister Carla, who was strong and decisive, Camila always needed considerable parental support. However, Carlos's death, together with Carmen's disease, changed this making Camila feel insecure leading to conflict with her siblings and disagreement about caring arrangements.

Family difficulties were therefore heightened by the disagreements and conflicts that occurred following Carlos death as the following account from Carla illustrates:

> ***Carla:*** *as I said before, the only problem I have is my sister, my youngest sister. We have any contact neither she makes things easier (…) I deal with my mother's condition better than with the problems I have with my sister. I know what my mother has and what it implies. But the thing is that my mother does not understand… Camila is her daughter and my mother prefers quarrelling, arguing with me before telling Camila something. My sister Camila is untouchable for her, you know? Then this is an inconvenience for me but… I know I will never ever resolve it. This is something that will always be here. I do not know what will happen the day my mother begins to get worse. I think my sister will go away.*

Reflections

The prior dominant family dynamic before AD was largely one of closeness and even at the beginning of the experience the family worked together. The whole group participated in decision making and shared caring responsibilities. Family members displayed open and honest patterns of communication and discussion.

However the unexpected death of Carlos caused a sharp rift in the family which impacted on family relationships by creating alliances between different individuals in the family. Under these circumstances family members were unable to reach agreement regarding caregiving activities so that conflicting dynamics emerged within the group, as noted above.

5.2.4 The Dominguez Family

The Dominguez family was made up of four individuals: Daniela, the person with AD, her children David and Delia, and her goddaughter Denia. While David and Denia, together with Daniela, agreed to take part in the study, Delia, her daughter refused. She always maintained a quite distant relationship with her mother and even though, following the onset of AD, there was a slight rapprochement between them, Delia decided to stay apart and not become fully involved in the caring experience.

Daniela was diagnosed with AD at 85 years of age. She lived alone at the point of entry to the study. She divorced when her children were still very young; neither Daniela nor her children had contact with her ex-husband. Daniela did not maintain any contact with any extended family members either. She had always been a very active and independent person, who rarely stayed at home. This was acknowledged by David when he described his mother '*my mother has never been the classic housewife'*, and explained that she had always been involved in many activities that did not leave her time to devote to her home and family.

Daniela lived in a rural district fairly close to the town. Her son David (aged 53) was also divorced and had a daughter who had no contact with anyone in the family. He lived in a house quite close to Daniela which helped him to take care of his mother. Denia (aged 62), despite not being a blood relative, was considered a sister and a daughter to David and Daniela respectively. Daniela had raised and cared for Denia since her childhood, after her biological parents decided not to take care of her. Thus the relationship between Denia and Daniela was special. Denia showed tremendous gratitude toward Daniela, who cared for her as if she were her mother.

Although David and Denia (and to a much lesser extent Delia) were organized in visiting and looking after Daniela, it was David who took on most of the care responsibilities and assumed a central role.

AD Awareness and Diagnosis

There was no family history of AD or any other type of dementia as far as the participants could recall. Daniela was diagnosed with AD in September 2012, though the family started noticing a decline in her cognitive function following a herpes infection she suffered four years earlier. The problems that Daniela showed in adjusting to the pain management treatment were seen by the family as the triggers for her increasing memory loss episodes.

Disagreements among family members, especially between David and her daughter Delia, in the perception that something serious happened to Daniela contributed to a delays (years) in seeking medical assessments and confirmation.

> ***David:*** *My sister said my mom had nothing, that she was fine. My sister still thinks completely different to me. She does not want to know anything. Then she denies it and does nothing.*

Diagnosis was provided to David and Delia and it was left to them whether or not to tell Daniela. They decided not to share the diagnosis with Daniela but talk about *'forgetfulness episodes'* with her. Despite this family decision aimed at preventing Daniela's suffering and discomfort, it also kept her without any real insight into the situation. Similarly Delia's attitude in justifying Daniela's memory loss as part of ageing (despite being well intentioned) had the effect of making Daniela resigned to her memory loss. As the following quote illustrates Daniela took a matter-of-fact approach to her condition, seemingly accepting what was happening to her was a reflection of her age.

> ***Daniela:*** *do not care about my memory loss. If I were 20 years old I would probably care about it but…*
> ***Nuria:*** *Why do you make such a distinction?*
> ***Daniela:*** *Because… for instance now, if I was meeting my friends and I could not assist because I'd had forgotten it, I would think: 'Oh, I am too old'. I always say the same: 'I am too old'. But when you are young you handle it anyway.*
> ***Nuria:*** *Then, I understand that age is…*
> ***Daniela:*** *Yeah*
> ***Nuria****: the reason…*
> ***Daniela:*** *Yeah. I've grasped it this way*
> ***Nuria:*** *You've grasped it*
> ***Daniela:*** *I've grasped it, yeah. (…) I do not care about it. I think the same way my daughter does: 'This is due to my age' (laughs)*
> ***Nuria:*** *This is what you daughter says about…*
> ***Daniela:*** *Yeah and I think this way too. What happen to me is due to my age. She usually say to me: 'Mom, don't worry, that's age'*

> **Nuria:** *Why does your daughter say that to you? Are you worried about it?*
> **Daniela:** *She may believe I am. Perhaps she… but I am not, I've already taken it in.*

This approach contributed somehow to the largely submissive role that Daniela assumed throughout the family caregiving experience. Also Daniela did not want to be a burden for her children as she understood that they had their own lives and she did not want to bother them, so she tried to go unnoticed as long as possible:

> **Daniela:** *Now they have children, grandchildren... they have things to do. I am little quirky... Why do they have to take care of me? Why they have to leave their children, their partner and whatever? I do not like that. I do not like to ask them for everything. I want to leave them alone, doing whatever they want.*

She even stated she would prefer dying rather than being a burden to her children:

> **Daniela:** *What about if one day I fall dawn and had to stay in bed. What would I do? Let it goes*
> **Nuria:** *Let it goes?*
> **Daniela:** *Getting an injection and let it go. Bye!*
> **Nuria:** *Why you think this way Daniela?*
> **Daniela:** *That´s something I've told my children thousand times. My son always says: 'You're crazy mom'. But the true is that I do not want they have to take care of me. I don't want to be a burden for them. Now I can still do some things by my own. But later..., to what purpose should I be here? Although they do not have little children but they have a family. I do not know. If my children were wrong this would be a torture for me. Now I cannot help them anymore.... God, I'm crying like a fool.*

Family Dynamics

Family relationships had always been a little distant and *'a bit forced'*, as David revealed in one of our encounters. This, unfortunately, was compounded by the presence of AD and the frequent disagreements family members had with respect to their caregiving activity.

David was considered the primary caregiver for his mother, although Denia provided him with lot of support in this activity. From the beginning they decided how to take care of Daniela. They spent the afternoons with her while in the mornings an external caregiver kept Daniela company and assisted her with daily activities such as cooking, cleaning the house and so on. Daniela was happy with this idea and said that she liked having someone at home who she could talk with.

At first this arrangement seemed to suit all the members of the family. However as time moved on, Daniela's demands for company and care increased. To respond to these changed circumstances David had to give up some of his regular activities, such as meeting his friends and going for a bike ride, and thus stay with her mother longer periods. Although this was still perceived as bearable, David began to experience a loss of freedom that he feared would get worse in the future, if he had to move to live with her, for instance:

> ***David:*** *Let's see. I see, from my point of view of course, I feel that we will reach a time in which I will have to move to my mother´s house and that will mean ruining my life. I do not know if you understand me. I will lose all my independence, my autonomy… The problem is that having not enough money to pay for a caregiver will mean coming here by force.*
> ***Nuria:*** *Do you feel you have lost independence?*
> ***David:*** *Well, by now… as I am not working I can manage to stay more days with her, that's not the matter. I come here twice a week and I deal with it. But the problem is on having to come here to spend the whole day. That would be… Now I am independent and do whatever I want and the way I want in mi house.*

The limited involvement of his sister in caregiving also contributed to David’s concerns for the future. Possibly the reluctance that Delia showed to engage in Daniela’s care was a product of long-standing distant relationships within the family. This is suggested in the following account that David provided during our second individual encounter:

> ***David:*** *Well, this issue shakes me easily (he started to get emotionally affected). I get... I try to handle this as positive as I can but often, those moments in which I am alone, although I love living alone, sometimes... All this is happening to my mother, especially... Let´s see, my mom´s situation affects me but the way my sister is acting also affects me. Then it is a bummer because after all the whole responsibly is mine and, my sister? She ignores the situation. Then this is a little heavy. I am the one who take on everything. This is not only about the time I spend with my mother but... my concern is that I see her like that and I do not have anyone to talk about. I mean, I have who to talk with but not as much as I would like. I do not know how to tell you. For example now I'm dating a girl, right? Then I do not like to spend all day like... you try not to talk about this to not bother the other person, don´t you?*
>
> ***Nuria:*** *How the relationship with you sister has been so far?*
>
> ***David:*** *It's never been quite good, but we deal each other more or less. It´s has been a bit forced. But recently it’s become worse, worse! Because as far I want to do something for my mother she just refuses to do it. She says that she is tired of my pressure on her, that she does not have to do anything for her mother, that what she is doing is more than enough. The alternative she gives on this situation is leaving our mother in a nursing-home. That’s everything she contributes.*
>
> ***Nuria:*** *(nods) and what about the relationship between your mother and her?*
>
> ***David:*** *It has not been very good ever. My sister has never had a good relation with me neither my mom so this is now affecting our situation.*

The expression *'this is a bummer'* proved a powerful image of the negative outcome of care for the son, worsened by previous poor relations with his sister. Nevertheless a measure of meaning and satisfaction could be found in his carer role, due to improving relationships with her mother:

> ***David:*** *Well, Denia she has always come to see my mother. She comes quite often. I used to come less than her; we just talked by phone or I came once a week. But now with this I come frequently. In that sense this is better because we are close to each other.*

Reflections

The dominant family dynamic here was of conflict and disengagement, with elements of hostility between siblings in evidence.

David remained acutely aware of Daniela's failing cognitive abilities and the need for increasing care in the future. By contrast Delia held a completely different perception, assuming that the situation was a normal part of her mother's life-stage. This and the distant interaction predisposed to family imbalance in responsibilities.

The inability to reach agreements in care decision making, based on prior poor relationships within the family, led to tensions between David and Delia and intensified ongoing conflict which was unlikely to be resolved in the future. As a result stress increased among those involved in the experience and led to caring being a largely negative experience for the family.

5.2.5 The Estevez Family

The Estevez family included Elena, the person with AD, and her six children, being three daughters, Ella, Elisa and Emma (aged 50, 48 and 47 respectively) and three sons, Enrique, Eduardo and Ecequiel (aged 45, 43, and 42 in that order). Although an extended family in which all members played a role in family caring, just Elena and her daughter, the main caregiver Elisa, took an active part in the study.

Elena was diagnosed with AD at 77 years of age, and lived with her daughter Elisa at study entry. Elena had been widowed for about 30 years and she lived alone in a large flat in the city centre until the onset of the AD. Her children had either married and left the family-house or moved to another city to find a job.

As stated above all the children were involved in caregiving, although at different levels. Except for Elisa, her siblings lived in other cities. However despite the distance, all of them moved to Pamplona at the weekend to spend time with Elena; Elisa, meanwhile, was responsible of her mother's care during the week. The fact that they were an extended family whose members worked together proved to be a significant resource in living with AD.

Elisa was married and did not have children. By contrast her siblings, except for her sister Ella, were married and had young kids. This seemed to influence the family decision that Elisa should assume greater responsibility for care during the week while the rest organized care during the weekends.

Following the onset of her mother's condition Elisa and her husband moved to live with Elena. Elisa worked as a comptroller of a large company and spent most of time at work; for that reason they hired a paid caregiver who was responsible for Elena's care until Elisa came home. Just before the study started Elena was admitted to a day-care centre where she was from 9am to 4pm.

AD Awareness and Diagnosis

Elena's mother (Eva) had AD that she developed in later life. Elena could not take care of her mother since her husband died unexpectedly as a consequence of a heart attack. This episode left Elena alone with the responsibility of taking care of her six children. Elena's sister assumed the vast majority of care for Eva and finally took her to live with her in another city. Nevertheless Elena maintained close contact with them and followed her mother's disease process closely.

This experience had an impact on Elena's personal AD experience, as was acknowledged by her daughter Elisa: *'My mother already knew what living with AD meant…'* Elena was diagnosed with AD in January 2012 and the doctor communicated it to her and her family. Unfortunately Elena's previous experience with the condition far from helping her to understand and accept the disease meant that she denied it.

Elena was becoming aware of the memory loss she suffered, however she had not accepted it yet. So whilst she recognized having memory loss, *'birds in the head'* as she called it, she strongly downplayed and denied the seriousness of it.

> ***Elena:*** *Don´t talk about it, it is not memory loss (upset tone voice)*
> ***Nuria:*** *what is that Elena?*
> ***Elena:*** *Birds in my head*
> ***Nuria:*** *Birds in your head*
> ***Elena:*** *Yeah (she laughs), but it is a silly thing.*
> ***Nuria:*** *And why don´t you want to talk about it?*
> ***Elena:*** *No. I want to talk about, but I do not think it is a type of memory loss to say…*
> ***Elisa:*** *Oh! I see; Alright!*
> ***Elena:*** *…she is doddering*
> ***Nuria:*** *No, but…*
> ***Elisa:*** *No, no, no*
> ***Nuria:*** *...her daughter did not say that*
> ***Elisa:*** *I did not say that mom*
> ***Elena:*** *But I have no memory loss*
> ***Elisa:*** *I see I see*
> ***Elena:*** *I have no memory loss (very upset tone)*
> ***Elisa:*** *Alright*
> ***Elena:*** *I say it now and I'll repeat it. Because what I do…*
> ***Elisa:*** *It's done*
> ***Elena:*** *Exactly! I do not think this is memory loss. At least I do not notice it. Well yes, sometimes I suddenly say 'Oh this, that or the other thing' but it's not memory loss as if…*
> ***Elisa:*** *to be worried about.*
> ***Elena:*** *I do not think so. At least I do not feel like that.*
> ***Nuria:*** *I see*
> ***Elena:*** *I do everything at home. I read everything… (From her voice tone I could appreciate she felt overwhelmed talking about it)*

The attitude of denial Elena displayed increased from the time she started attending the day-care centre, as Elisa commented later. Furthermore this required her children to act as if nothing serious had happened to their mother; otherwise Elena showed an evident displeasure.

Family Dynamics

Family relationships had historically been close as Elena and her daughter reported. According to Elisa the unexpected death of her father brought to the family a strong sense of responsibility and support for each other: *‘when my mother was left alone in charge of us we all learned that we had to collaborate’.* This past experience translated to the present dynamics within the family so that even though the children lived independently and were separated by distance, there was strong support for each other. All members shared a common sense of family commitment, based on respect and cooperation.

The family were also staunch Catholics and relied on their Christian faith to cope with the caregiving experience. When I delved into the religious orientation as a support resource for the family in living with AD Elisa stated: *´faith helps us to understand the family and its purpose to service other members of the family who are more vulnerable’.*

Being an extended family in which everyone was willing to work together helped the family to live with Elena’s disease while also maintaining their separate lives. Despite their own complex lives they had a practical approach to problem solving that shared responsibility between them. However the preferences of Elena were not fully considered at all times.

Although Elisa, the daughter, assumed the major caring responsibilities she felt well supported by her sisters and brothers. This prevented her from feeling burdened and left her time to enjoy her weekends. The fact that all of them were involved in family caring made their experience more bearable. Likewise the ability they have to clearly defined responsibilities and roles for each member contributed to family organization and well-being:

> **Elisa:** *We are currently organized well. Fortunately, thank God I have five siblings. Because if I had not had them, I'd have died... Now I know why families rely on nursing-home care...*

The approach the family adopted in accepting the condition also played a part in reducing emotional imbalance. Overall the family considered the condition was something that came to them as part of life and which they had to deal with:

> **Nuria:** *How did you all feel when you knew your mother had AD?*
> **Elisa:** *How does a person who has cancer feel? This is what came to us.*
> **Nuria**: *This is what came to us*
> **Elisa:** *I do not know. I have not a feeling of… This is what came to us and that's it.*

Emotional displays were practically nonexistent within the family. They tended to approach the condition from a practical perspective which allowed to them laugh about difficult episodes they might face:

> **Nuria:** *Do you talk about this in the family?*
> **Elisa:** *We laugh fundamentally*
> **Nuria:** *You laugh*
> **Elisa:** *I think it is better laughing about it than crying (laughs). Well, we sometimes cry as well but, but we tried to talk about things that happen to each other when we are with our mother - look what she did to me last day- it's better to laugh about it.*

The family possessed a strong ability to resolve problems and overcome difficulties that arose during the care process. Decision making was based on rational foundations rather than emotional reactions. The family used consensus to generate as much agreement as possible between members. However Elena's voice (the person with AD) remained largely silent and decisions regarding her care did not fully respect her preferences, as in the case of attending to the day-care centre.

> ***Elisa:*** *(...) this has been the best option because... when I got home (after work) I had to stay with her, I had to do lot of thing with her... and in the end I felt exhausted, ex-haus-ted! ready to drop!' I think that you have to take some distance, a little distance from this. You cannot do other thing. This is about you or her. And... I'm so sorry but a fact of life is that she goes first. This may sound harsh but... this is how you need to take this matter. Otherwise you may die first.*

Reflections

The dominant family dynamic here was primarily one of closeness, with friendly relationships between members. Decision making was directed to the wellbeing of the majority, although sometimes this overlooked Elena's preferences.

Family members became involved in caregiving due to a strong sense of co-responsibility. This pushed them to work toward agreements in the distribution of care responsibilities and thus improved family organization. Effective communication patterns also contributed to this. Caregiving contingencies were candidly discussed. The willingness all members to cooperate and share responsibilities in care acted as a family strength in living with AD in the best way possible.

5.2.6 The Gonzalez Family

The Gonzalez family comprised three individuals; Gabriel, the person with AD, and his daughters Gemma and Gabriela; Although Gabriela was involved in the experience she lived in a different city and decided not to take part in the study.

Gabriel was diagnosed with AD at 77 years of age, and lived alone at the point of entry to the study. His wife died a few months after receiving the diagnosis. This was a traumatic and crucial period for the family, which also increased instability and emotional stress during the first few months of the AD experience.

The death of Gabriel's wife, which the family believed was due to a failure in medical care, predisposed the two daughters into a defensive attitude against health care professionals. This was noticed during our first encounter in which the daughter repeatedly complained about the poor professional care her mother had received, a fact that as she explained seemed to repeat in her father's case. What was clear was that the close occurrence of the two events resulted in greater family suffering and stress that impacted on the family response to caregiving.

Both Gemma (aged 52) and Gabriela (aged 54) were married but had no children. This situation facilitated their organization of care for Gabriel and the two sisters initially decided to proceed by taking care of their father one week each:

> ***Gemma:*** *Well, for now we are quite novel in this situation. Then we've organized this by doing one week each one. My sister lives far away; She lives in Barcelona but she is not working at present. I mean she is unemployed and then she is free. She has no children. I do have children neither then, this is a bit easier. Once I knew the diagnosis of my father I asked for a work-leave because I wanted to be with them, caring for and accompany them.*

AD Awareness and Diagnosis

There was no family history of AD neither any other type of dementia as far as the participants could recall. Gabriel was diagnosed with AD on June 2012, though Gemma, recalled initial encounters with uncommon behaviours from 2006. The feeling that something serious was happening to Gabriel went on for an extended period of time, contributing to delays in seeking medical assessments and confirmation.

> ***Gemma:*** *Puff! That's not his signature, that's not. He signed totally different. My father's not signed as he did before since 2006. Although we got the diagnosis in 2012, by 2006 something had already happened to him. Then, when did this start? Puff! I think that by the time families realize that something happens to them… these thing was developed many years ago... ten, fifteen years ago… Some things had already occurred in his brain. Maybe, there are some*

> *areas in the brain that don´t make these things visible. They cannot be identified and then… Because I use to think: ‘Look what he did in 2006’. I remember episodes such as one day we met and he was too late; while he is a very punctual person. At that time he misunderstood the time we were meeting. He confused the time he had an appointment with the mechanic with the time I were meeting. I do not know! Then, I believe that this (the AD) had already started. Other episode I remember was... One day, something wrong happened to him when he was driving on the road. That episode frightened me. He was a really good driver... so, when this started? Many years ago! He drove in the opposite direction at a roundabout. It was terrible! However, as this incident did not take place here (in a familiar place)… I do not know I did not pay more attention to it...*
> ***Nuria:*** *(nods)*
> ***Gemma:*** *I do not know!*

Gabriel was aware of the difficulty he had in finding the right word while maintaining conversation. However he did not associate this with the condition as he understood that the problems he had in remembering were as a consequence of his age.

One of the aspects that caused major stress for Gabriel was the initial overprotection he experienced from his daughters. He had always been a very independent person, with set routines. Thus his daughters’ vigilance was not well accepted, leading to tension and hostility between Gabriel and his daughters.

> ***Gabriel:*** *At this stage of life, memory? I do not confuse anything. I still go to Pamplona by my own. Perhaps I do not remember some dates, names... But the thing is that sometimes you do not let me do the things I want to do.*
> ***Gemma:*** *What types of things dad?*
> ***Gabriel:*** *You know*
> ***Gemma:*** *is this about money?*
> ***Gabriel****: money and more things.*

> **Gemma:** *you would like to have more money in your wallet, wouldn´t you?*
>
> **Gabriel:** *I do not need anything. I just need you both do not overcontrol me (oppress/ keep down)*

Family Dynamics

Relationships for this family had always been close and friendly. Gemma, the daughter, described her family in our first encounter as follows:

> *'We are a normal family. We get together as other families do. Although my sister went to study abroad and I moved to live alone quite young we used to meet each other. We had had good relationship, cordial relationships…'*

Family members were relatively independent from each other but they shared a sense of responsibility for providing support and help to each other, as suggested by the rapid action that his daughters showed in taking care of their parents once Gabriel's diagnosis was confirmed.

From the beginning both daughters collaborated and assumed caring responsibilities. Family organization seemed to work at first. All members of the family agreed that the daughters took care of Gabriel on a weekly rotating basis. This allowed them time to enjoy with their partners and keep their usual routines while Gabriel felt secure living in his house and maintaining his regular activities.

However resentment among the daughters began quite early in the process. On the one hand Gabriela, who lived in another city, saw disparity in the individual efforts she and her sister made in caring for their father; she had to move to live with Gabriel while Gemma only spent few hours with him. On the other hand Gemma, who lived near her father, considered she assumed greater responsibilities and number of tasks.

> **Gemma:** *(...) I mean, we all are sick; actually it is not just my father who is sick; it is that we all are. We feel overwhelmed and everyone experiences this in a different way. Each one has its own needs. I see myself deprived*

> *of freedom; my sister does too but in a different way. She has to come here and her husband is there and then… To me? Yes I come here but I'm with my husband; but when she is here, she is here. Although my brother in law sometimes comes here, that is true, but, but, but... Such a mess!!*

It seems that both Gemma and Gabriela displayed limited flexibility in their caregiving responsibilities. Each wanted to maintain their lives with as little disruption as possible and so they tended to act in parallel rather than in a coordinated fashion. Poor communication also contributed to this. Both parties failed to understand and respond appropriately to the needs of the other and thus they could not cooperate fully. Without good communication there was no teamwork but misunderstandings and conflict arose. A simple but significant example of the poor communication there was in the family was highlighted by decisions about how much money Gabriel would take on a trip he had planned to do. Gemma explained how difficult was for her to receive an answer from her sister.

> **Gemma:** *It is really hard to get an answer from her. One day we were having lunch and… it was about a week to my father went for a trip so I asked them about how much money he should take to the trip because he has some difficulties in managing the money. You know what? We finished having lunch, she left home and I am still waiting her answer. I had to decide by my own. When this type of things comes out, she starts talking about other things, we move to other issues and thus we do not take the decision that really matter.*

Gemma further explained that given her sisters attitude she had frequently made decision on her own, which was resulted in increasing resentment and friction.

Certainty disagreements and misunderstandings among sisters impacted on relationships and nature of the care experience everyone:

> **Gemma:** *I do not know, I do not know. Now everything is between us, between us. Obviously this affects my father as well*

Such conflicts heightened concerns about the future and how they would respond as care needs increased:

> ***Gemma:*** *I see that quite soon it may be very difficult to stay with him at home. It may be very difficult, very hard! Because now I feel that I have no freedom, if now I feel this way... I have to help him to dress, I have to help him to bath, he wakes up constantly at night and when he gets up he disorganizes everything, everything. Then I say, Oh God! How are we going to organize? That's what, what really bother me. I have some ideas of… but, but I say 'no, no, no, no, that is not…' I see that lot of work is coming to us, and specifically to me. I can perceive it. Because, because my sister is there and I am here… yes, even if we have someone who may take care of him, even if we have five people… These people need to be organized and you have to control them. That's the point.*

Reflections

The initial family dynamic here was one of closeness, with friendly relationships. At first members of the family showed a willingness to get involved in caregiving and they organized it together. However, as time progressed and care demands increased, members of the family, especially the daughters, did not seem to have similar expectations so conflict emerged within the group.

Inability to reach agreement about often small decisions was not helped by poor communication patterns leading to misunderstandings. This led to the situation in which one family member tended to make all decisions leading to resentment and as a result conflicting family dynamics were emerging.

5.2.7 The Jimenez Family

This family was comprised of five members: Justina, the person with AD, and her husband Jaime, and their three daughters Jimena, Julieta and Juana. Justina was diagnosed with AD at 72 years of age, and lived with her husband Jaime, who, at the point of entry to the study, she had been married to for 48 years. When Justina and Jaime entered the study they were 72 and 75 old respectively;

and their daughters, Jimena and Julieta, aged 38 and 46. Juana (aged 48), although was involved in the experience, did not take an active part in the study.

The couple lived in a house located in a rural area at some distance from the city. Julieta, one of their daughters, lived in the house next to them. She was married and had two sons (aged 19 and 20). She worked in her own business which allowed her flexibility to help her father with Justina's care. Julieta's husband and her sons maintained a really close relationship with Justina and Jaime, thus Justina's disease profoundly affected all of them. It had such the impact that, as Julieta acknowledged, she initially could not talk about the disease with her husband and children. Initially Julieta's husband and sons refused to believe that Justina had AD as the following quote illustrates:

> ***Julieta:*** *We cannot talk about it with my father but, I cannot talk about it with my family either. Fortunately now it seems like my husband is more open to… he has started saying: 'Well, let's see how we can...' He's accepting that my mother has memory loss so now I have the possibility of talking about it with him. Until not long ago he said 'I do not want to talk about this, your mother is fine; don't bother me with such a thing'.*

Jimena, for her part, lived in the city centre with her partner. She had no children, and worked as a full-time psychologist in a centre for young people experiencing difficulties. She organized her daily life to spend at least two days a week at her parent's house. She had done this since she became independent and left her parent's house. However after the onset of AD she took special care to spend time with them.

Juana, the oldest daughter, lived in the city as well. However she had always been very independent, living her own life, so her relationship with the rest of the family was friendly but distant.

AD Awareness and diagnosis

There was no family history of AD or any other type of dementia as far as the family could recall. Justina was diagnosed with AD in January 2013. An episode of temporo-spatial disorientation suffered by Justina, when she was in a familiar place, led the family to seek medical assessment right away. They first went to their GP who attributed the episode to the ageing process. This was at first accepted by the family until similar episodes reoccurred and became more frequent. Consequently the family insisted on a reassessment of Justina’s health status and she was finally referred to the neurologist. Neuroimaging evaluation did not provide conclusive data and unfortunately for the family, their accounts of daily episodes were not seen as significant by the specialist who took no further steps to confirm the diagnosis.

Jimena, motivated by the uncertainty and suspicion that something was happening to her mother, decided to attend a course about neuropsychology. Surprisingly for the family obtaining diagnosis stemmed from that course rather than following the conventional health care system.

> ***Jimena:*** *We have been dealing with this issue since 2007. We went to the neurologist and the neurologist said: ‘well, there is nothing. It is a matter of ageing’. Well, then great! Fortunately I attended a course on neuropsychology and met Psychologist A and Psychologist B (popular psychologists in the local area of Navarra); and they made a case in which I saw some characteristics of what was happening to my mother. So once the course finished I explained to Psychologist A what happened to my mother and then she explained me everything. Thanks to her we are here otherwise I do not know what would have happened.*

As the above quote suggest, the period around diagnosis was difficult for the family with a delay being the consequence.

Justina was completely aware of difficulties she was experiencing and the implications these had for her life. During our first encounter she showed profound concern about the progressive and incurable nature of the condition and the intrusiveness this had:

> **Nuria:** *What do you think about (the forgetfulness episodes that her daughter talked about)?*
> **Justina:** *if this is going to be like that all my life, it is better to die soon.*
> **Nuria:** *'It is better to die soon'*
> **Justina:** *I do not know. I used to do thing by my own. I was able to do things that I cannot do now. Now I cannot do them.*

The whole family experienced a continuous and profound sense of loss and subsequent grief as they lived through the changes associated with the course of the condition. Justina suffered as her prior self-image crumbled away and the family grieved both for the losses that were occurring in their lives and the loss of Justina.

> **Jimena:** *This is as grief in life; this is how I call it. She is alive but you're living, you're living a loss, as if she had died as if… because you are losing your mother.*

Adjusting to loss and accepting the disease were among the most significant and challenging issues this family faced, especially for the husband. Justina's husband did not take part in the study as, according to the daughters, he was so emotionally affected that was unable to verbalize his own feelings and thoughts. He had not yet accepted his wife's condition and this caused increasing dispute between the couple and the rest of the family.

The main strategy that the whole family adopted from the beginning was that of protecting Justina. The family controlled and carefully watched her activities to prevent something happening to her. However too much control eventually ended up hurting Justina's feelings:

> **Julieta:** *Now we care for her. She cannot go alone and such things*
> **Justina:** *I think you care too much. You and your father*
> **Julieta:** *I admit that I overprotect her.*
> **Justina:** *She and my husband… Tut!*

As a result of her families' overprotection Justina started to 'hide' certain episodes from them to prevent them getting overly concerned and to limited their attempts to control her.

Family Dynamics

Relationships within the family had always been close. Therefore, the present conflicting dynamic was a major concern to everyone. The family defined themselves as a close family with good emotional bonds, in which mutual support was based on affection and attachment to each other. Proof of this was the profound suffering and emotional impact that the situation caused to all family members.

The emotional impact of the condition and the consequent perceived 'loss' of Justina was very painful for the family. Members experienced difficult emotions that prevented them moving on. As the following quote illustrates, family members and especially Justina's husband had not fully accepted that Justina had AD. This response to the condition caused confrontations between them:

> ***Jimena:*** *This is affecting all levels in our family relationship because my father… he complains, I think my mother does certain things we do not understand; anyone does. Then we try to find the logic, but there is no logic. Thus my father gets desperate. There are times we all get upset with her. She also gets upset and thus we all argue with each other; we argue because she make things that have no sense to us an then my father starts: 'how can she do something like that?'*

The non-acceptance of the condition also affected the family response to change. For instance, changing family roles and responsibilities proved to be a painful and intricate process that affected family relationships for the worse:

> ***Jimena:*** *Yes. Change is very difficult to both sides. My father is the classic men, the one who has ever done nothing. And today he is the one who takes care of her medication… their roles have exchanged*

> *and that's difficult for everyone. Firstly for her, and then for all of us who are around. This change has been huge!*
> **Justina:** *From doing nothing to now doing many things.*

Each member of the family seemed to grieve their loss in a different way and the intensity of the emotions they went through varied. This worked against family balance and organization as the emotional impact the family suffered caused distance between members and raised conflict and disagreements regarding family care, as stated by the following daughter:

> **Jimena:** *and organizing between us. I'm afraid because we are pouring over each other our discomfort. If we just fight instead of working together to solve the… We are doing that, confronting each other instead of resolving… We are not resolving but discussing. Then if we continue this way! I think: 'perfect! (Irony tone) We are getting angry each other. Then instead of working together to get solutions and seeing what we can do, we are worrying about 'who makes more than the other one', 'you make more than me' and 'you should do more'. Then this is a matter of recognizing how each other can contribute and thus organizing a bit this situation; because it is getting more complex and we just discuss. We are on this right now.*

As with other families, the Jimenez family adopted a day-to-day approach to dealing with the future. Therefore instead of focusing on facing the challenges that might arise the priority was to take advantage of the present. There was a belief that living in the present was the most satisfactory way for everyone, especially for Justina, as Jimena declared:

> **Jimena:** *Then rather than uncertainty I feel nervous, this is going to get worse, is going to get worst, then we have to advantage of the present situation.*

Reflections

The dominant family dynamic here was one primarily of closeness. Emotional bonding was and remained strong although conflict occurred at some point.

The emotional impact of the condition and the resulting loss of Justina prevented the family from moving on. Far from working together, the emotional impact the family suffered raised conflict and disagreement in organization and care decision making.

However it seemed that if the family could accept the condition and their new situation, they could regain stability and positive dynamics since high level of commitment to family existed.

5.3 Impact of AD on Family Dynamics

Whilst each family case study was unique it was possible to discern experiences that marked out the potential early impact of AD on the family and to use this to suggest a typology of family dynamics. These could be characterised as

- **Close dynamics at the start and throughout the experience so far**.
- **Close dynamics at the start which became conflicting.**
- **Conflicting dynamics at the start and throughout the experience so far.**
- **Conflicting dynamics at the start which became closer**.

These suggest the ways in which family dynamics might change following the onset of AD. Broadly speaking it seemed that families whose relationships had been characterised by affection and commitment were more likely to remain close despite the everyday challenges they encountered in living with AD. This helped them to find meaning in their caring activities and to see the positive dimension. Conversely families that perceived caregiving as an obligation and/or had poor prior relationships were more likely to have difficulties in reaching agreement and their relationships were likely to remain conflicting. In these two scenarios AD mirrored existing patterns of working and being in families.

However in other cases the opposite could happen and families who were close initially could become conflicted and those who were conflicted might move closer together as they worked to address the challenges AD posed.

Therefore, the data suggested that closeness and conflict in family dynamics may 1) pre-date the onset of AD and be based on existing interactions within the family or 2) develop as a consequence of the impact that AD and caregiving had on the group. These possibilities are explored more fully below.

5.3.1 Close Dynamics at the Start and Throughout the Experience

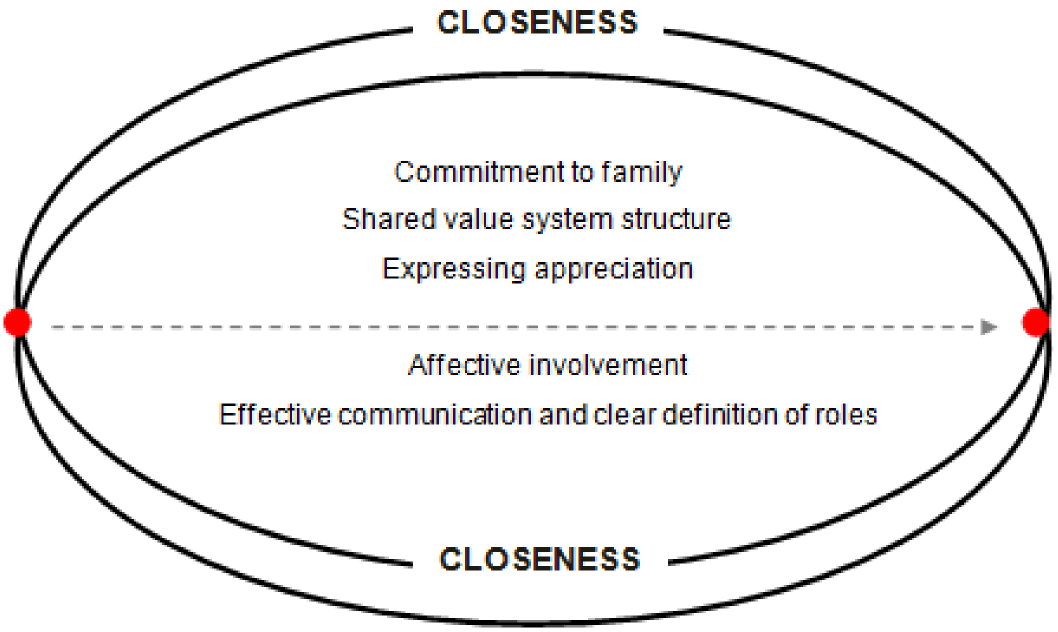
This describes families that started and remained close throughout the care experience. Strong emotional bonds and friendly family relationships pre-dated the onset of AD. It was the most positive dynamic found in data and the Armendariz and Estevez families most closely reflected this dynamic.

The considerable levels of trust and affection that members of the Armendariz family shared proved to be central in helping them to find balance during challenging circumstances and as a result they experienced family growth. Caregiving was considered a family commitment, thus family members emphasized the ‘us’ rather than an ‘I’ experience. As a consequence the AD experience was lived as family rather than as a group of individuals.

With regard to the Estevez family the willingness all its members to get involved in caregiving was a strong feature. This was a major source of strength that meant the family were able to remain positive in the face of AD. Clear role definition within the family facilitated family organization as everyone knew what their responsibilities were. Clear channels of communication between members of the family facilitated negotiation and ensured that agreement was reached to the benefit if all.

It was clear that good prior family relationships, commitment to family and willingness to get involved in caregiving were key factors that contributed to these families maintaining a positive dynamic. This is captured in the figure below.

Figure 5.1 Typology of family dynamics: close dynamics at the start and throughout the experience



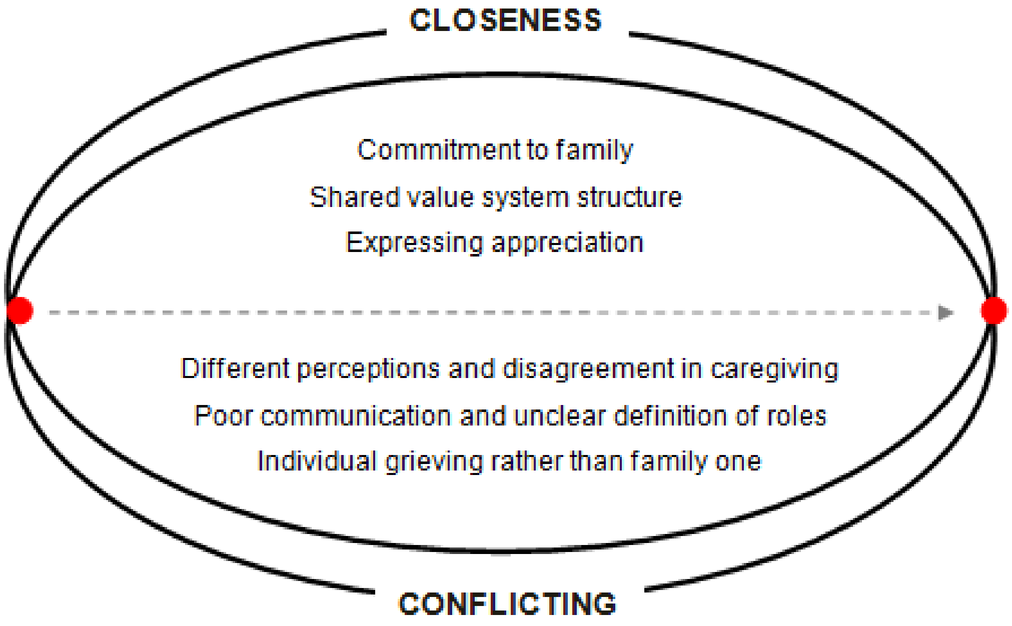
5.3.2 Close Dynamics at the Start which became conflicting

This dynamic reflects the case of families that started close but became more distant and conflicted over time. Although good family relationships pre-dated the onset of AD, the impact that the condition and caregiving had on the family caused disagreement and conflict that families were unable to resolve. This dynamic emerged among the Cervera, the Gonzalez and the Jimenez families.

In these particular cases families found it difficult to reach agreement on caregiving roles and responsibilities. Misunderstandings between members occurred and intensified the conflict and stress experienced. For example in the case of the Jimenez family, the great emotional impact that the condition and the resulting loss of the person caused the family accepting the new situation and dealing with the challenges it posed. Each member of the family grieved the loss in a different way and intensity which distanced individuals from each other.

Rather than being able to work together members of these three families confronted each other. Although there was affection between them, disagreements regarding care ended up dominating family interactions. Communication was difficult, or non-existent in some cases, which did not allow members to form a shared view or to feel that their opinion had been listened to. This impacted on the perceptions of roles and responsibilities resulting in imbalance and resentment within the group. This is reflected in the figure below:

Figure 5.2. Typology of family dynamics: close dynamics at the start which became conflicting



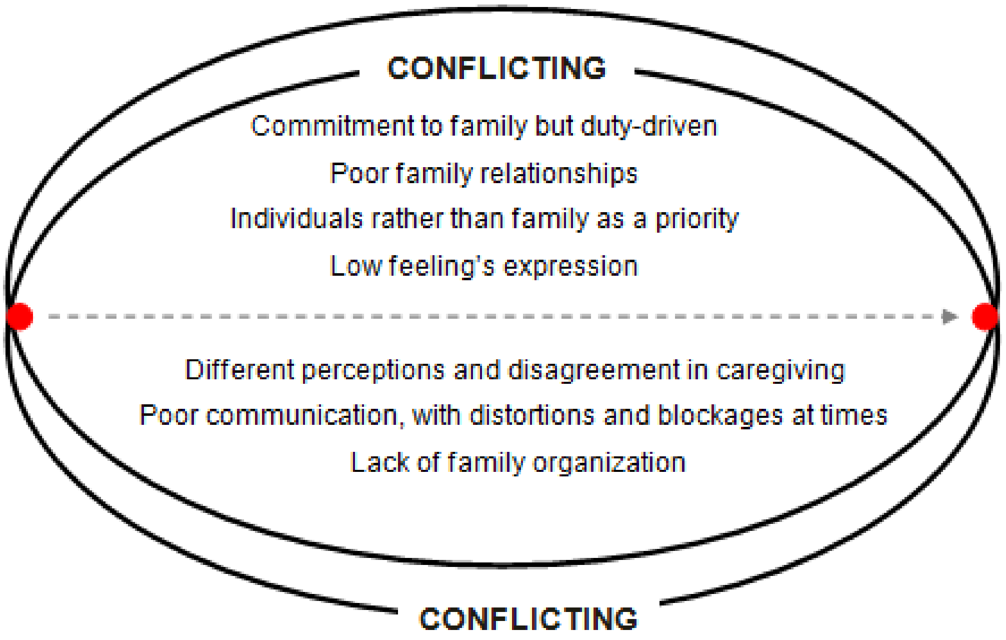
5.3.3 Conflicting Dynamic at the Start and Throughout the Experience

This dynamic reflect families that started and remained distant and conflicting throughout the care experience. Poor family relationships pre-dated the onset of AD, and this was the least positive dynamic found in data as was evident in the Dominguez family.

Disagreement and disengaged relationships was a main feature of existing relationships and this remained the case in the face of AD. Members lacked a sense of family unity and primarily worked as individuals and this prior dynamic affected the level of involvement each member of the family adopted in caregiving, causing imbalance in the distribution and sharing of task and responsibilities. AD exacerbated this situation intensifying ongoing conflict within the family which seemed unlikely to be resolved in the future.

Families with a conflicting dynamic looked at future through a lens of fear and trepidation. Care was experienced as a burden so members were unable to find positivity and meaning in the experience, as the figure below illustrates:

Figure 5.3 Typology of family dynamics: conflicting dynamic at the start and throughout the experience



5.3.4 Conflicting Dynamics at the Start which Became Closer

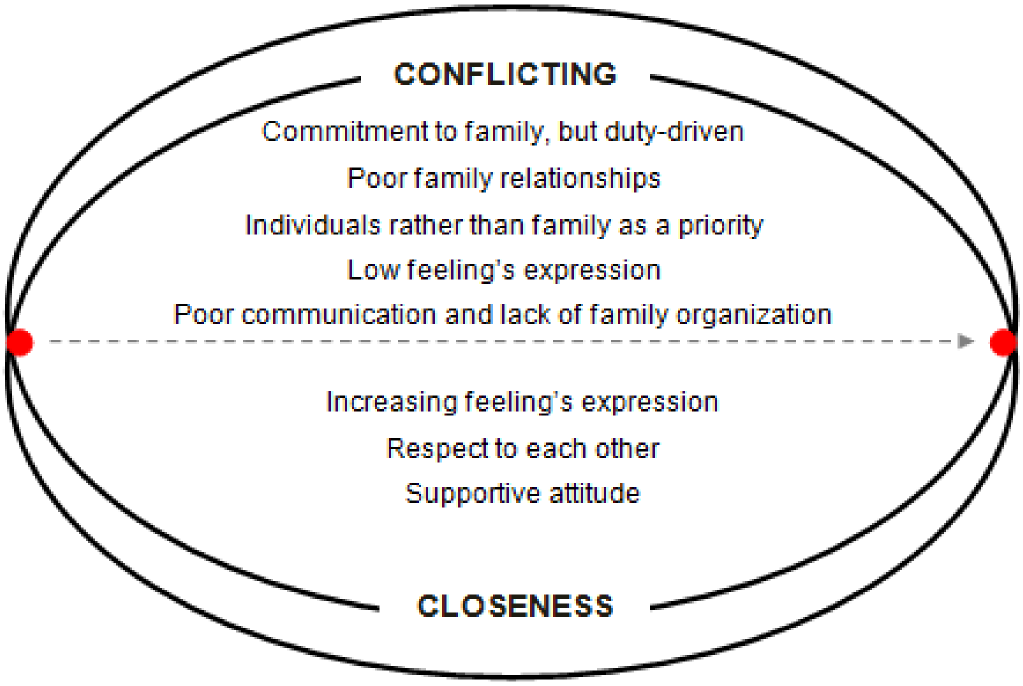
This dynamic captures families that had conflicting relationships prior to the onset of AD but for whom the experience served to bring them closer. Although none of the families in my study entirely reflected to this dynamic, the Blasco family shared a strong affinity to this.

At study entry conflict and disengagement dominated the Blasco family. Thus the onset of AD and the caregiving experience were initially perceived as a burden. However, as the family was required to be in closer contact with each other overall relationships and patterns of communication slowly improved. But this was not universal.

At the outset relationships between certain members were particularly strained. They found it difficult to manage their feelings and were intentionally hurtful and aggressive to each other. Here AD intensified this tension until a permanent rupture occurred in the family. This event, although painful in nature, had a positive impact on relationship in the rest of the family.

The frequency and quality of communication among the remaining members changed for the better, allowing more opportunities to share feelings and to reach agreement. As a result respect to each other increased and the family was able to find some common ground. Although burden did not completely disappear mutual support made this easier to handle.

Figure 5.4. Typology of family dynamics: conflicting dynamics at the start which became closer



Summary

The case studies of each of the seven families participating in the study informed the development of a potential typology of family dynamics which illustrates how these could either remain the same or change over time in the face of AD. This provides a context and background against which to view the three stage temporal model of the subjective experience of living with early stage AD that is presented in the following chapter.

CHAPTER 6

DEVELOPING A TEMPORAL THREE STAGE MODEL ON THE SUBJECTIVE EXPERIENCE OF FAMILIES LIVING WITH EARLY STAGE ALZHEIMER DISEASE

Introduction

The previous chapter presented a case study of each of the seven families participating in the study and considered the ways in which Alzheimer Disease (AD) had appeared to impact on family relationships and dynamics. This resulted in a potential typology of family dynamics which illustrated how these either remained the same or changed over time in the face of AD. This chapter builds on this temporal aspect and presents a three-stage temporal model of the subjective experience of families living with early stage AD. References to the family case studies as well as the typology are used to explore the key social process that underpinned each stage of the model.

This chapter will describe each stage and build up the resultant temporal model step by step. This will unfolds as follows:

- Firstly, the ***'what's going on here'*** stage will be presented. This comprises the initial process of *'noticing',* through which the family became aware that something was not quite right. In the face of this recognition a range of reactions emerged involving activities such as *'justifying'*, *'disagreeing'* and '*hiding'*. Later the process of *'noticing'* changed to one of *'suspecting'* in which the family became more purposeful and vigilant in trying to understand what was happening to their relative with, as yet undiagnosed AD. At a later point, as the suspicions grow the family engaged in the process of 'confirming' which involved actively seeking a medical diagnosis. Subsequently 'noticing', does not cease but transforms into the more active process of 'watching' which is maintained over time throughout the family experience.

- The second stage of the model, ***'our life is changing',*** captures the realisation that, in the presence of AD, family life is affected in fundamental ways. Here the key social processes of 'watching' and 'redefining' emerge. By engaging in the process of 'watching' the family became more aware of the changes that were occurring in their lives. This realisation led them to start to *'redefine'* existing roles and responsibilities, relationships, everyday life, and their vision for the future to try and maintain stability in family life. Tensions and challenges between the need to maintain family stability and to redefine the way the family works occurred in all families. However as the previous chapter suggested in some cases these difficulties were resolved, in others they were not.

- The third stage of the model ***'Keeping things together'*** revolves around the basic social process of 'balancing'. This describes the way that families worked together (or did not) to preserve and create a balance between their caring role and preserving a semblance of life as it had been before the onset of AD. Families who could find such balance were better able to integrate living with AD into their lives whilst maintaining closeness in the family, as suggested in the prior chapter. In contrast families that failed to find balance struggled 'against' the AD and this caused, or exacerbated, difficulties in family dynamics. The case studies presented in the previous chapter will be used to illustrate how these processes operated.

The above account seems to suggest a rather linear transition between these stages but in reality it was more complex than this with a circular and iterative relationship between the stages over time. So for example the need to ask *'what is going on here*' recurred over time as the condition progressed and a new balance had to be sought.

An overriding theme that emerged across all three stages was the families perception of ***'feeling abandoned'***, which captures the experiences that families had in their contact (or more often no contact) with the professional support provided at each stage of the AD process. The importance of countering this perception of ***'feeling abandoned'*** by providing more adequate and tailored support is one of the key implications to emerge from the study. This will be considered later in the discussion chapter.

In keeping with the tenets of the GT, the findings are presented with the support of verbatim quotes that best capture the family processes identified, paying particular attention to include as many participants' voices as possible (Charmaz, 2006).

6.1 *'What's going on here'*

Stage 1 of the model was named *'what's going on here'* and is underpinned by the key social processes of 'noticing', 'suspecting' and 'confirming'.

In the opening series of family interviews I sought to focus on the beginning of the families' experiences and thus encouraged participants' narratives to follow a logical time sequence as far as possible. My intention was to explore the early adjustment to AD; therefore the following open question was posed: *To start, could you tell me about when you/your relatives' 'memory loss' episodes started and how you noticed them?*

Despite variations in the interview overtime each first encounter with the families commenced by asking the same question. Thus, as a result, familes' narratives were particularly rich in providing examples of the initial awareness of the condition (yet undiagnosed) as the following quotes illustrate. Each of these describes some behaviour or event that was unusual enough to catch the attention of the family or involved established personality traits becoming exaggerated. Sometimes, as a number of the quotes below illustrate, families began to attribute causes to these different behaviours:

The Armendariz Family (1):

> ***Anne:*** *Well, he got confused. For example, he had never gotten lost while driving before. We both have gone to Malaga (the place they went for holidays every year) a hundred times! We have a house there.*

Adela: *Well, initially it was like if he had lost a bit... well, like if he had lost the time-reference. I mean, you told him something and then… Things progress and evolve, don't they? They follow stages, and my father remained stuck in the past, in previous episodes that had already happened, I do not know, I do not know, perhaps fifteen days ago, right? Somehow that was what made us… We didn´t alarm him* (Memo: again a protective attitude occurred?) *but we realized that there were some, some anomalies, yes.*

The Blasco Family (1):

Bea: *Well, perhaps this got worst. As my sister has already said, my mother has other pathologies. I mean, my mother has always had her quirks. She is a woman… a little weird woman, with her quirks. I mean, you have to tiptoe around her.*
Beatriz: *Always being careful about what you say and what you do.*
Bea*: And what you do! Because she's always been so suspicious, really suspicious! And now this is exaggerated! (…)She used to tell me things about Blanca, my sister: 'look! Blanca has come into my house. I miss a sweater and I found it in her house', this kind of things. Then I replied to her: 'mom, you're confused, that's all'. I was not concerned at that time. But one day she said to me again: 'Look, Blanca has entered home'. We did not have any key, because my mother has never wanted to give us a key.*
Beatriz: *And if, and if we got the keys she changed the lock*
Bea: *Yes. She has changed the lock four times*
Blanca: *She has already changed it four to five times*

The Cervera Family (1):

Cecilia: *Then, at that time she (mother) began to say things that frightened Carla, my sister. For example: 'Let´s go to the school your* *brother is waiting for us', when my brother had died years ago. She also got up and did not get the toilet on time.*

The Dominguez Family (1):

David: *She is currently 85 years old. When she aged 80 she got herpes, she received a strong treatment and since then we noticed that... the treatment affected her head. … It is since then we noticed her…*
Nuria: *So you think that the herpes was the initial…*
David: *The trigger or whatever. Thereafter we noticed that her memory loss episodes intensified.*

The Estevez Family (1):

Elisa: *But the most evident episode was, apart from the cluelessness she had at first, when in November a year ago, we both were talking to each other and when she (my mother) talked to me, she referred to me as if I were her sister. She thought she was talking to her sister. And then I said 'this is not, this is not a normal cluelessness'.*

The Gonzalez Family (1):

Nuria: *Okay. So you've just mentioned that sometimes you find some troubles in…*
Gemma: *Yes, yes*
Nuria: *…getting the right word, don't you?*
Gemma: *Yeah, That´s why we figured it out, yes.*

The Jimenez Family (1):

Jimena*: It was due to a lost episode, in time and space. Because she was in the centre city and then she said she did not know...*
Justina*: I did not know where I was.*

Since my interest was focused on the whole families' initial awareness and adjustment to AD, and not merely that of the caregiver, I also actively explored any initial 'noticing' by the person with AD. Their answers provided a variety of accounts about what could be the first time the person had registered their own memory loss:

> ***Abel:*** *Look, I sometimes… now this is decreasing, but I started perceiving that I sometimes forgot certain things I used to remember, names of familiar people and things like that.*
>
> ***Barbara:*** *Well, I felt very sad. It's like now… Some days I'm alright and other days… I do not know! I am as if I had lost my memory.* (She provided two examples of spatial loss. One of them occurred when she got off the bus she took daily to go to the centre city and the other one happened when she was shopping in a familiar supermarket).
>
> ***Carmen:*** *I have poor health (…) Poor health because, because for some time now I'm crying a lot. 'Why am I crying again and again?' I'm crying all the time for my husband, my parents, my children, my son, the one you see there* (she pointed out a picture in the room).
>
> ***Daniela:*** *Until a year ago or so I remembered everything that had happened in the past; since I was a child, everything! And now, this is leaving me. Now I cannot remember this past stuff. And I feel sad, because I knew my entire story.*
>
> ***Gabriel:*** *I do not get confused and nothing similar. I still go for a walk around Pamplona by my own (…) But, I struggle in getting some words and… but sometimes I get up, I go for a little walk and then the word maybe comes out.*
>
> ***Justina:*** *For example I noticed that on occasions, while I was talking about something with someone and he or she told me something, I was like…* (She illustrated with her face a blank stare) *and he or she*

> *said to me: 'what's wrong with you?' 'I do not know! I've just forgotten it'.*

The 'noticing' experiences varied substantially among people with AD and relatives, possibly due to the differences in levels of knowledge and awareness of the condition that existed within the family. Furthermore, there were also notable differences in providing early awareness experiences among people with AD. While some of them made reference to explicit early episodes, others provided general accounts of changes they noticed in themselves in comparison with previous behaviour. Even at this early stage there were marked differences in the accounts of some members of the family and the person with AD. The latter would often play down or even sometimes deny that there was a problem.

For instance Abel, the person with AD in the Armendariz family, believed that his forgetfulness was decreasing, and suggested that his situation was improving. He stated: *'my situation is not extreme'.* Abel's position may explain why the family adopted a largely protective set of behaviours, with his wife Anne in particular seeking to protect him from anything that would damage his self-esteem as discussed in the case study in the prior chapter. However well-meaning this meant that Abel was not fully aware of what was happening to him and thus that he could not take a more active role in his care and the decision making process.

In the case of the Estevez family, Elena, the person with AD, did not welcome the idea of talking about her memory loss and she became upset when her daughter Elisa raised the issue. Rather, as the quote below suggests she sought to trivialise anything that could be seen as being related to a failing memory. Therefore the 'noticing' experience could not be fully explored with her at that time as the comfort and wellbeing of participants prevailed at all times.

> ***Elena:*** *I have no memory loss (very upset tone)*
> ***Elisa:*** *Alright*
> ***Elena:*** *Exactly. I do not think this is memory loss. At least I do not notice it. Well yes, sometimes suddenly I may say: 'Oh this, that or the other thing' But this is not a memory loss as if…*

> *I do everything at home and, and I read everything (from her tone of voice I could detect that she felt overwhelmed talking about it)*
>
> **The Estevez Family (2)**

On the one hand Elena's account seemed to reveal that she did not associate the *'birds in her head'* she referred to with the onset of AD. Furthermore she considered them a *'silly thing',* an issue without apparent seriousness. On the other hand, the number of assertions she made that what happened to her was not memory loss emphasized her attempts to deny the noticeable difficulties she was experiencing. As stated in the family biography Elena had already had prior family experience with AD and this may meant that she did not want to acknowledge the possibility of her having it herself.

This stance caused Elena considerable effort and left her with feelings of insecurity, despair and sadness, as well as leading to confrontations with her family. The way that the family handled this had an important impact as they decided to reinforce rather than confront their mother's perceptions and to adopt a *'nothing happened to her'* approach. Whilst this might have been functional in the short term, as it avoided conflict with their mother, in the long term it made it very difficult to acknowledge and deal with the situation as it worsened over time.

While analysing the accounts that the families provided about their early awareness it was clear that the idea of 'noticing', understood as a growing awareness that something was happening to the person, was far from being immediate but was a process that took time to take come to the families' attention. Indeed as will become clear one of the most prevalent early responses was to seek to 'justify' and therefore explain apparently 'odd' events within a normal frame of reference.

For example unusual behaviour was attributed to a recent life event such as a death in the family, or increased demands on a person's time and energy, or even as a 'normal' part of the ageing process. The following fragment of an interview with Elisa, the daughter of the Estevez family, illustrates this gradual process which carries on until something occurs that it is not really possible to 'justify':

> ***Elisa:*** *One day… Well, this came as a result of some comments from my sister in law. She is a doctor and lives in Pamplona. She said to me: 'your mother dotes a little, doesn´t she' and I said: 'Don't care; this could be something normal due to her age'. And it wasn't, it wasn´t. But I thought that it was something normal in older people. She (my mother) also lived alone at that time so we did not pay close attention to that, that…*
>
> ***Nuria:*** *changes*
>
> ***Elisa:*** *…changes, that´s it. But for example one day my mother said: 'I do not how to get your house'. Going from her house to mine, even by car, is not too easy! Luckily she broke her arm, she broke her wrist and then she decided to stop driving. Thank God! Otherwise I do not know what would have happened.*
>
> ***Nuria:*** *(nods)*
>
> ***Elisa:*** *That episode worried me little bit. Also, one thing that used to bother me was that when I went back home the doors of the Kitchen cabinets were all open. She found nothing… Then I said myself: 'Why are all these doors open?' Plop plop plop… I closed the cabinets and that was all. I didn't realize!*
>
> ***Nuria:*** *I see, I see.*
>
> ***Elisa:*** *But the most evident episode was, apart from the cluelessness she had at first, when in November a year ago, we both were talking each other and she (my mother) talked to me, she referred to me as if I were her sister. She thought she was talking to her sister. And then I said 'this is not, this is not a normal cluelessness'. And then we went to the clinic…*
>
> **The Estevez Family (1)**

As Elisa's account demonstrates, she initially ignored certain of her mother's unusual behaviours and looked for rational explanations (the ageing process in this case) that justified such behaviours and thus confirmed that there was nothing to worry about. Even though her sister in-law had already made some reference to the cognitive status of Elena, Elisa chose to ignore this until something occurred that was impossible to overlook, i.e. that her mother thought that her daughter was her sister. This was ultimately the trigger that led Elisa to consider that her mother's behaviour was not simply as a result of her *'normal cluelessness'* and professional help was sought.

Some relatives did not fully understand the unusual behaviours they encountered or their importance. In these situations they made light of the episodes and saw them as nothing to be worried about. But once again realization eventually dawned that something was far from right:

> ***Carla:*** *My dad said to me 'Look what your mother has done today! She has cooked an omelette without eggs'. At that time you laugh about that. You not think that these are little things to care about but…*
> ***Carmen:*** *me? I can believe I didn't put eggs in the omelette*
> ***Carla:*** *You know… males! They do not pay attention to such as things; but I finally did it. What's more, lately when I called my mother to see how she felt, she said to me: 'hold on, I am coming in a while'; then she left the phone and she did not answer any more, such things. Then, at the time she lived with me, while my father was admitted at hospital, I clearly noticed that. I said myself: 'OMG! This is not normal'. This happened in July; we went to the neurologist in October and he (the neurologist) gave her some medication, made the CT and the process ran really quickly. Everything happened so fast.*
>
> **The Cervera Family (4)**

As families began to notice more they also started to become 'suspicious' that perhaps things weren't right and could not be attributed to other causes. As Carla, one of the daughters said she then started '*keeping an eye'* on her mother's behaviours.

'Suspecting'

As the above two accounts illustrate the nature of the unusual behaviours increased in severity and frequency, or new behaviours emerged, it became increasingly difficult to justify these and so initial 'vague' suspicions that the relatives had, moved to a strong perception that *'this is not normal'*: Unfortunately, the period between first 'noticing' and becoming more openly suspicious often took an extended period which delayed seeking professional help in obtaining a diagnosis.

This delay was in part due to the 'hiding' actions undertaken usually by the person closest to the older person with memory problems. Hiding was therefore most commonly performed by the partner of the person with AD. They tended to temporarily hide information about the unusual behaviours, especially from their children. If the children did not live with their parents they often failed to notice things themselves and had to rely on the accounts they were given, as recounted by daughter Cecilia below:

> ***Cecilia**: Our father did not tell us everything. He told perhaps one thing among five. Then, we did not live with them... if you do not see her every day you may notice anything. In just two hours (when you are there) you may notice nothing.*
>
> **The Cervera family (5)**

This *'hiding'* strategy was reported by some of the daughters that took part in the focus groups. Maria stated that in her family it took almost three years from the time her father began noticing unusual things in her mother before they got the diagnosis. She acknowledged her father did not tell her about his wife's behaviour and as a consequence there was delay in the process of seeking confirmation:

> ***Maria:** Perhaps in my case this delay in time came as a result of my father's attitude. We began to suspect that… Look, I am the daughter and I did not live with my mother so… once I start noticing this I found out that my father had already started to notice something by 2003; and we got the diagnosis around 2006-2007. It was quite difficult among my siblings and my father to… It is very hard to see that your mother is not alright, isn´t it? We also had some problems with the GPs because… yeah, they made some tests, but the tests did not detect any problem, and we… at that time I was sure that…, perhaps*

> *my brothers were less certain about it, but my father was also pretty sure there was something wrong but he did not want to tell us. That's why we lost some time. Yeah, at that time we lost time.*
>
> **FG.3**

Given that the uncommon episodes initially occurred only sporadically and the person with (potential) AD was still able to continue doing things more or less as usual, 'noticing' was much easier if the family lived with the person with AD than if they lived apart. However once noticing became more common place in the family (and if family communication was good) then suspicions began to be shared. But this process still often took a considerable time, especially if various members of the family did not agree, as David explains below:

> ***David:*** *Well, It took time. Because since you start noticing something, that this may be or may be not… Both of us, my cousin and I, perceived that my mother was not alright. But my sister said that it was not like that, then… But clearly now she is getting worse little by little. We have been like this about 5 years.*
>
> **The Dominguez Family (1)**

This issue was also raised in the focus groups. The following dialogue between daughters who participated in one of the focus groups provides an elegant account of the 'disagreeing' that occurred between members of their families when discussing whether or not something was happening to their relatives:

> ***Ilda:*** *I noticed it quite soon. I noticed my mother had Alzheimer while she was living a very normal life.*
> ***Nuria:*** *did you hear about the disease before?*
> ***Ilda:*** *I'm pharmacist then…*
> ***Nuria:*** *So did the experience you had help on…?*
> ***Ilda:*** *No. I think you notice it (easily). I was very worried, and then I lived the situation you mentioned before, that your brothers tell you: 'hey, you are so nervous', 'you are hysterical'. I know I am, I'm really very nervous, but I soon noticed...*
> ***Nuria:*** *What did you notice? How you noticed it as you said?*

***Ilda:** In particular situations at home. My mother has been very meticulous; she has been a good seamstress. She started doing things... rarely! But I noticed that she was weak. In fact at that time, she travelled, she went to the social club and she was very active. But whenever she went out with her friend, I said to her 'Louise, take care of my mother please, I do not feel confident of her behaviours'. I saw things I did not like. There wasn't an event, a specific event that worried me. No, there wasn't. But she was not my mother. She was very sad (...) I was really worried for a long time; my family told me that I was crazy. Until I got it; I took her, I took her to the clinic: 'Let´s go!' I had to convince my brothers that I did not like the story (situation) I was seeing.*

Inma:** In my case it was evident. But the truth is that it was like that because I was living with her 24 hours a day. But when they (people with AD) live alone and their relatives go to see them just for a while… I understand that this may be more difficult. For example, my sister used to say to me: 'What are you talking about! Nothing happens to mom!' There is nothing wrong with mom!' even though I used to tell her: 'Something wrong is happening to mom'… There was no one in the family with Alzheimer and I had never thought this would be Alzheimer. I would have never imagined this would be Alzheimer. But I noticed she was not herself**.

***Irene:** Not living 24h with her may make you get confuse.* What's more, *you never want that 'this' to be 'what it is'*

***Isabel**: Yeah. I also lived this matter with my brothers. According to my brothers my mother was great, what I said was bullshit, bullshit! My sisters were more realistic, perhaps because they spent more time with her but…*

Irene: Look, *my mother's been diagnosed with Alzheimer three years ago, and my brother still tells me: 'mom is great; mom is great'. Yeah sure, he grabs her at 14:30, they go for lunch at the restaurant, he makes her laugh and then he takes her back home... of course she is great! (ironic tone) But if you are with her for a while, when she gets*

> *up five hundred times to lift the pot, then you will see how happy you are! (ironic tone)*.
>
> **FG.1**

It is clear that the description of her initial realisation provided by Ilda was based on the intimate knowledge she had of her mother. This prompted her to think something was happening even when her mother was living an outwardly normal life. This locates subtle 'noticing' in the context of an intimate relationship which allows people to recognise abnormalities far sooner than others who are unfamiliar with the situation would be able to. This intimate (or expert) knowledge held by families is, as will become clear, often overlooked or even discounted, by professionals.

However, as the above passage of dialogue shows not all members of the family attended to or acknowledged such behaviours in their relatives. Indeed people who did recognise them and shared their concerns with siblings were often 'written off' themselves (*'Hey! you are so nervous, you are hysterical'; 'what are you talking about? nothing happens to mom'; 'mom is perfect, those things are up to you'; 'you're a little loopy'*). As Irene noticed denying that something was wrong sometimes remained even after a formal diagnosis was given.

Clearly reaching agreement that something serious was happening to their relative was not an easy task for some families. However, it was of the utmost importance as until there was agreement then people would not seek professional confirmation and avoided getting a timely diagnosis, causing unnecessary delays.

Over and above the 'justifying', 'disagreeing' and 'hiding' activities described above, a 'hiding' response from the person with undiagnosed AD also played a role in delaying confirmation of the diagnosis. People with (as yet undiagnosed AD) often noticed certain changes in themselves, such as slight forgetfulness that they sought to cover up. These responses, largely identified by the relatives only in retrospect, were interpreted as a defensive reaction to the idea that something serious might be wrong, as this threatened the older person's sense of self:

> ***Isabel:*** *In fact, whenever she had some memory lapses, … she tried to turn it around, tried to find… she tried to justify it. She even continued doing so until recently. That was amazing! Such a capacity she had to downplay it!*
>
> **FG.1**

This failure to acknowledge potential problems could cause difficulties for family members, especially spouses. Lucas, a husband that participated in one of the focus groups, explicitly acknowledged that before he sought medical support and confirmation he needed his wife to agree that something was wrong. Eventually after failing to do he approached the GP himself, who suggested that a degree of subterfuge might be needed:

> **Lucas:** *The most important… let´s see, the most important thing is that they, once you notice the lapses, that they accept, that they recognize that they forget things. That's what you need to take them to see the doctor. For me it was the hardest thing. This took me a year. She did not want to go because she said she was fine and that she did not forget things, when tut! It was very obvious that more and more…. I had to go to see the doctor alone. He told me: 'Bring her here, as you can, by cheating her… I want to check her; I want to make some examinations and so on. We are going to make some tests and let's start from here'. Right away from doing the test he told me 'no, no, she needs to go to the neurologist'. I mean, it was the beginning, but it took me time. The delay you have mentioned comes from there.*
>
> **FG.2**

The 'hiding' behaviours of the person with AD sometimes continued after the diagnosis had been given. This was described by Gemma, who along with her sister cared for her father with AD:

> ***Gemma:*** *He hides the episodes*
> ***Nuria:*** *He hides them*

> ***Gemma:*** *Yes, and you are the guilty one. If he can he saddles you with the blame. If you say something to him or if you point out a fault… I used to do it but now I am not doing that way. For example yesterday, the keys were out of the door and I told him that. But he did not believe me! In this situation it is as if you were fooling him. So now it is better to say nothing, nothing. Forgetfulness? Nothing, nothing.*
>
> **The Gonzalez Family (2)**

Again here the daughter decided to adopt a *'nothing happened to him'* attitude and thus avoided disagreements and confrontations with her father. But this was also motivated by a desire to prevent suffering in the person with AD. However the value of this strategy over time was questionable, as will be discussed later.

> ***Carla:*** *My mother has no recent memory, you know what I mean? She does not remember what she did yesterday, so she became upset. If you say to her that this is not… if you tell her that she has done or has not done this… she does not accept it. Then, there are times she realizes that…*
>
> ***Carmen:*** *I remember everything*
>
> ***Carla:*** *(…) If I left her for three months, she would not remember me.*
>
> ***Carmen:*** *Oh God!!*
>
> ***Carla:*** *Mom, you understand what I mean? You have no recent memory. I cannot ask you about something that happened yesterday because you do not remember it.*
>
> ***Carmen:*** *Look I have remembered something that happened to me few days ago (she was getting upset)…*
>
> ***Carla:*** *What?*
>
> ***Carmen:*** *…when I was in the social club and I´ve already told her'*
>
> **The Cervera Family (3)**

> ***Jimena:*** *Then there are times in which we even get upset with her; we say something to her and she gets upset as well. Thus many times we discuss; we discuss because she makes something that has no sense, then my father say: 'how could she make something like*

> *this?' We may also say to her: 'How could you do this?' Then she realizes what she has done and she gets upset. I think this reaction is also based on the suffering she feels for her own loss.*
>
> **Julieta:** *She is also suffering, because she realizes it; then of course she suffers…*
>
> **The Jimenez Family (2)**

‘Confirming’

As it is apparent above there were often periods of considerable delay before professional help and a formal diagnosis was sought. However, despite this and the growing recognition that something was clearly wrong, the receipt of the diagnosis itself was a difficult period for the family causing confusion, distress and suffering. The following dialogue, which occurred in one of the focus groups (FG.2), clearly illustrates how traumatic this period was, something that was not helped by the wider ‘system’. This was not an isolated event as the differing experiences below indicate:

> **Lucas:** *I got angry with the doctor, with the neurologist. I was for nearly a year hearing: ‘well, let's do this, we’ll do some tests and we'll see... It may not be...’ Hence the doubt was there. But when I went back to visit the neurologist and he told me: ‘well, your wife, I consider she has a probable AD’; I replied to him: ‘What are you talking about?’; Then he said ‘I’ve already told you last time you were here’; ‘Last time you did not say anything to me. You said that it may be possible this was not...Then I clung to the idea that it could not be possible and now, out of the blue, you tell me this’; ‘Please calm down, calm down...’; ‘I calm down, but what did you expect? It comes as a shock, what I may do now?’; ‘Do not worry, I will refer your wife to the memory unit program and thus she will start with some cognitive training sessions...’ Well it took more than four months but finally we went there and I talked to Dr. A (the psychologist of the centre) who made some assessments to my wife. But he told me: ‘at first it was considered that your wife would attend the memory unit*

program. But she cannot be admitted because her level is lower than expected so she would not be able to follow the activities that we develop in this program'; 'Then, what can I do now?'; 'Firstly I am going to refer you to AFAN (the association). You do not need to worry, there you will find all the steps you have to follow; so please do not worry'. Well the psychologist gave me lots of instructions but he also 'gives a sharp thrust'. When I went to AFAN I was really afflicted. So B, the psychologist of the association, started to follow my case and my wife was admitted in a day-care centre and she is still attending to the centre. But initially it (the diagnosis) came as a shock and it was hard to keep going...

Laura: *I expected it. I mean, we had noticed it, since 2010 we were seeing that the depressive episode did not improve at all and, she did not get better although she attended the memory unit program... therefore, it was a shock despite they did not tell you 'the word' (Alzheimer). But I did not realize what it really meant till one night my dad called me: 'here I am with your mother. She does not want to go to the bed till her husband come here'. Then I said 'OMG!' Because you may know what AD is but you do not want to think about what it implies. I thought 'Well my mother is cognitive alright, she has some forgetfulness...' You did not want to delay it but the episodes were not so evident. But when my dad called me at that time was a shock. I realized what happened. Then, you live with it, you adapt to it.*

Lisa: *My case is quite similar to theirs. She started with some treatments for depression, stress... She has always been really nervous. Then we noticed she did not follow the treatments and instructions her psychologist gave to her. So the psychologist referred her to the neurologist. The process was quite similar to their process... It took so much time. I decided to talk with the psychologist because if he, who it is supposed to be the professional, could not work with my mother what could I do? I thought that referring to the neurologist was the easiest solution; he found nothing so I decided to visit a private psychologist. He was very famous here. Well my*

> *mother couldn't follow the treatment he gave to her either but… they made some tests; and finally they said she suffered from AD; quite similar to your process. Navigating thought the public health care system that as I am noting from your talks we have to lash out at public health care system.... public and private. Health care system in general.*

The period surrounding diagnosis was often an important and traumatic one for the family. They sought an expert opinion to confirm the seriousness of what they were seeing but most of time a medical consultation did mean reaching a timely diagnosis. Unfortunately for the majority of the families interviewed the process of obtaining a diagnosis was a complex and prolonged one and involved a lack of information and limited support. As the last participant above noted there was a need to *'navigate'* the system and this is something that will be returned to later when the final category, that of *'feeling abandoned'* is considered.

The Temporal Dimension of 'Noticing'

As was noted above the 'noticing' process was what first alerted families to the possibility that something was wrong. However 'noticing' was not confined to this period alone but rather continued throughout the journey but changed in nature and character over time. Thus as the condition progressed families noticed a series of on-going physical, psychological and social changes, as described by David below:

> **David:** *My mother is getting worse little by little. I've already start noticing she has some challenging behaviours, as this is known. She is, my mother is not violent; she is not aggressive but, now she does not want to take a shower, she does not want to get up, she does not want... I mean, she is doing these atypical things... She may say to you: 'I have already taken a shower' and thus she refuses to do it. She has started doing those types of things. Apart from that she is still pretty docile. I've also noticed she no longer talks as much as she did before. Before, we had pleasant conversations. Now I see that when I speak to her she is absent, she does not pay attention to what*

> *I am saying and I need to repeat everything. Anytime you say something she asks you over and over again, you know? Besides she may tell you: 'long time not seeing you'; and you were with her the day before.*
>
> **The Dominguez Family (2)**

Others noted how long held personality traits and aspects of the person that had defined them began to slowly disappear. For example a wife noted how her husband '*no longer had 'that thing' he had had before'.* She pointed to the loss of her husband's dynamism, which had previously been a defining characteristic of him as a person. From her account it seemed as if this salient element of his identity had gradually faded away:

> **Anne:** *This affects everything. In the past he was very, very dynamic. He has always been working away from home (…)*
> **Nuria:** *Anne, how do you see your husband at present?*
> **Anne:** *I feel as if he no longer has 'that thing' he had before. I've also noticed he is a little absent.*
>
> **The Armendariz Family (2)**

Others noticed how behaviours which had defined their parent in their eyes were now no longer present, and as a result their whole image of their parent had begun to change. This became a major source of stress for these children:

> **Blanca:** *She has always been very, very polite; she has always showed us to have good manners. But now! Going shopping with her is… You do not know the fuss she may cause.*
> **Bea:** *In fact she no longer cares about anything.*
> **Blanca**: *Yeah. She even swears; when she has never ever used a bad word.*
>
> **The Blasco Family (4)**

> **Julieta:** *My mother has always been an active person, that in addition to working outside she worked at home. She took care of everything. She was strong, a very hard-worker and a very autonomous person in*

> *some way. So what I think now it is being too hard for us is seeing her as a dependent person; because somehow now she depends on us and that's the principal emotional change we are living.*
>
> **The Jimenez Family (2)**

Likewise as I explored the changes that people with AD had noticed in themselves, they spent time recalling aspects of their life before the onset of the condition. Such memories proved to have an emotional impact since the loss of self became more evident to them when they compared the ‘prior’ and ‘the now’. This could have a significant impact on their perceived quality of life, causing some to reflect on the value that their lives now had:

> **Barbara:** *I feel I have poor, poor memory. I can no longer do anything like I did before.*
> **Nuria:** *what type of things?*
> **Barbara:** *Well, having walks, going out... I`ve forgotten where the shops are and I cannot go alone anywhere. I do not know where the stores are, where this store is. Neither this nor that! Nothing! I have forgotten everything. I have forgotten everything! I know nothing. Cooking, I have forgotten how to do it. Sometimes I call them (my daughters) and say ‘Hey, how do I have to cook this?’ Before that I was a very good cooker and all people come to have lunch at home, my daughters and so on. Now dear, I cannot do it. I know nothing. Nothing is anything. I am just, I am just thinking of dying. Because I feel I am worst. I would say I am not going to live for a long time. I say that to my daughters: ‘I'm going to ‘the other side’ quite soon girls’ and they usually say to me: ‘Mom, do not say that please’.*
>
> **The Blasco Family (3)**

> **Justina:** *if this is going to be like that all my life, it is better I die soon.*
> **Nuria:** *‘It is better to die soon?’*
> **Justina:** *I do not know. I used to do thing by myself. I was able to do things that I cannot do now. Now I cannot do them.*
>
> **The Jimenez Family (1)**

> ***Jimena:*** *The other day she said: ‘if...’ There was something about Alzheimer on the TV and she said: ‘If that is what is happening to me I will jump from the terrace’, ‘why you are going to jump from the terrace!’ And when we came back from the doctor, she also asked: ‘Then, is this going to be like this forever? and I said to her: ‘Well mom, you will go slowly forgetting some...’ and she said: ‘So, Am I going to end up in a wheelchair, sitting as a furniture?’, I said: ‘Mom, I do not know!’. The worst thing is that she realizes it, she does not accept it, neither let us help her. That's the worst part.*
>
> **The Jimenez Family (4)**

In the face of such changes people began to realise that things would never be the same again and this heralded the emergence of the next stage that is termed *‘our life is changing’.*

6.2 ‘Our life is changing’

‘*Our life is changing’* was identified as the second stage of the family AD experience and this was underpinned by two key processes termed ‘watching’ and ‘redefining’.

‘Watching’

At this stage family care did not require providing much practical assistance but was defined initially by a more active form of ‘noticing’ which was termed ‘watching’. This meant, observing the person closely and keeping an eye on his/her activities and behaviours. This was often done discretely so that the person with AD was unaware of it. Therefore while it did not involve hands-on care activities nevertheless it was acknowledged as being stressful and demanding by relatives as they many felt constantly on edge.

> ***Adela:*** *Now mom, you are who keep an eye on dad*
> ***Anne:*** *Yes, I care for everything. I have this kind of distress; you know what I mean?*

> **Adela:** *Yeah. She is always alert, she is always watching*
>
> **Anna:** *I am always...*
>
> **Adela:** *Yes. Always, always watching everything! She is always acting like that. As a result she gets... (At this point of the interview the daughter made some gestures with her face illustrating that her mother got nervous easily because she was always trying to control everything)*
>
> **Anne:** *Yes, I feel a little bit nervous.*
>
> **Adela:** *She is always alert.*
>
> **Anne:** *Well, but I am not obsessed with this*
>
> **Adela:** *I know that mom. But anytime my father goes out she checks if he has taken the keys; what he has taken and what he has not taken.*
>
> **The Armendariz Family (1)**

The repeated words of Anne: *'I have this kind of distress', 'I feel a little bit nervous'*, highlighted the stress and effort this type of 'care' could bring to families. This idea was reinforced by the accounts of other relatives who described their constant vigilance, such as, where he or she went; what he or she did or did not take before leaving home; what time he or she would be back home; how he or she was dressed; and what he or she had or had not eaten.

During this still early stage families expressed the profound fear that something might happen to their loved one, as they became concerned about their abilities to maintain their own safety. It was this fear that motivated families to adopt a 'watching' brief in order to keep track of what the person did or did not do. This was not a simple task, as in many cases the person still lived relatively independently and wanted to maintain their usual routines:

> **Jimena:** *I am afraid that something worse may happen to her. Because sometimes she goes for a walk and she does not let my father know; that worries me a lot. There could come a day when the phone rings, and she is lost and no one could find her. I am really afraid that despite watching her closely... this is the worst part to me. This stresses me the most; if she was not cared I would don't mind.*

> ***Julieta:*** *Yeah. But you know, sometimes she goes out and you don't hear she leaves home.*
> ***Jimena:*** *That is what scares me. That despite looking at her quite close, watching her all the time… something like that may happen to her. I am really afraid about this.*
>
> **The Jimenez Family (2)**

This aspect of family care was also seen as being very demanding by the families in the focus groups. They all agreed that 'watching' was one of the most stressful aspects of caregiving. A daughter who cared for her mother with AD, described this aspect as being *'as if your heart would escape though your mouth'* (FG.3). The following dialogue with some of the daughters who took part in the first focus group provides a clear account of the 'watching' processes that took place in families and reinforced the difficulties it posed, partly because of its rather secretive nature:

> ***Inma:*** *The times she went out with her friends…these resulted in too much stress for me. I called her and if she said: 'no one has come here, no one has come'. You created yourself stress, asking yourself 'what is she doing? Will have she gone out with someone?'… Later she started attending the day-care centre; that way she was alright and I was alright too.*
> ***Idoia:*** *When she went to the church I thought: 'It is 10 and she has not come yet. Quarter past ten and she has not come, twenty past ten and still she has not come...' then I was... She always went alone but I followed her in secret to see how she went . But in the end this situation was a stressful situation because you had to make sure she did not see you.*
> ***Isabel:*** *We also followed her to see if she got lost or not.*
> ***Ilda:*** *I think that everybody controls this type of patients. Because when I was working, how many times could I call her? Twelve times, eleven times, eighteen times... Before she went to the church, after she got back, before she had lunch, to know what she was going to eat for lunch, after she had lunch, to know if she had eaten. And, to*

> *make matters worse, if she did not answer the phone I took the car and flied off... I've had traffic fines, even a car crash...*
>
> **FG.1**

It seemed there were two main reasons that this was particularly stressful. Firstly the efforts that relatives made to try and keep some sort of control over the situation without at the same time 'taking over' the life of the person with AD. As was noted above during the early stage of AD the person still wanted to continue with his/her regular activities and routines such as going to the church, going for a walk after lunch and attending the social club. Frequently these activities did not involve other members of the family, and were often things the person with AD did alone. If for whatever reason the activity took longer than it normally did and the person with AD was late back from church for instance then the families became very concerned. The uncertainty involved heightened feelings of both powerlessness and distress for the family. Secondly, again as noted above, some family members resorted to what they saw a subterfuge and for example tried to follow the person with AD secretly. They felt very ambivalent and guilty about this.

As new changes occurred and were noticed over time it was impossible for the family to maintain this distant 'watching' any longer. Therefore watching became a more overt activity that it was difficult to keep from the person with AD. Some people did not appreciate this and saw it as being rather oppressive, they '*doesn't let me breathe'*. This was explicitly expressed by Gabriel and Justina, two people with AD:

> ***Gabriel:*** *Sometimes you do not let me do the thing I want to do.*
> **Gemma***: We do not let you do what you want? What kind of things?*
> ***Gabriel:*** *Some things*
> ***Gemma:*** *Having more money?*
> ***Gabriel:*** *Money and other stuff*
> ***Gemma:*** *you would like to have more money in your wallet, wouldn´t you? I know you would like it.*
> ***Gabriel:*** *I do not need anything; I just need that you do not overwhelm me*

> **Gemma:** *What kind of things makes you feel overwhelmed dad?*
> **Gabriel:** *You are constantly telling me what to do*
> **Gemma:** *are we?*
> **Gabriel:** *you know what I mean. You do not even let me breathe!*
>
> **The Gonzalez Family (1)**

> **Justina:** *Sometimes I scold my daughters. They are too… especially Jimena and Julieta. They start: 'Mom this, mom that…'; 'Leave me alone please!' 'Don't put those clothes, I've prepared these one for you'. They decide my clothes and everything; my shoes…, everything I have to wear, and I say to them: 'Leave me alone girls! I will wear whatever I want'.*
> **Nuria:** *Could you tell me a bit more about how you feel when they act like that?*
> **Justina:** *I feel that they do not let me breathe. As I usually say that to them: 'Girls, you don't leave me breathe'. And if I do something wrong, for example in the kitchen, if I get confused with something they are at once quarrelling. Jimena does it less often, but my second one, Julieta, she is more… She is always saying 'Mom, go slowly please'; She used to leave everything prepared for me so I do not have to look for them, but…*
>
> **The Jimenez Family (3)**

Paradoxically this perceived overprotection by the family tended to increase the 'hiding' behaviours of some people with AD. As a result the family redoubled their 'watching' efforts and the potential for a 'vicious' circle emerged.

Justina, for instance, frankly admitted that she did not share everything that happened to her with her family. For example she was beginning to have some difficulties in her interactions with fellow attendees at the social club who were commenting unfavourably on her now more noticeable 'forgetfulness'. She made a conscious decision not to tell her family in case they prevented her from attending anymore, as despite these difficulties she still enjoyed attending the club:

> ***Justina:*** *I do not want to say nothing to them, to Julieta, because then she'd say to me: 'don´t go to the social club anymore'*
>
> ***Nuria:*** *So you do not tell your daughters?*
>
> ***Justina:*** *Sometime I tell them something, but not everything, not everything. (…) If I have a bad day and they ask me: 'Mom, what's wrong?' I say to them: 'I have a bad day, that's it'. That's it. This way they are more relaxed. Otherwise they are going to be more and more on guard. And I do not want that.*
>
> **The Jimenez Family (3)**

Maintaining a balance between 'watching' the person and not exerting too much control over him/her clearly resulted in difficulties for the family. However, as was pointed out by people with AD, excessive control served to constrain them and make them feel disempowered. This ultimately meant them adopting more hiding behaviours so as not to worry the family. This in turn made the family increase their vigilance. Other families decided to take a more relaxed attitude and not to be too concerned if certain things, such as standards of appearance or dress, started to slip.

> ***Elisa:*** *Well she no longer knows how to dress on her own*
>
> ***Nuria:*** *Does she need full supervision to do it?*
>
> ***Elisa:*** *Look, I do not fully supervise her. If she does not put her bra, I do not care, I have no problem. The thing is that her external appearance is more or less alright. I have to manage to hide the pants and socks she has already used to prevent she uses them again. She does not want to have a shower and then there is no way to do anything with it….*
>
> **The Estevez Family (1)**

In addition to this watching and preventative role family care at this point also had a protective dimension with the goal of aiming to maintain the self-esteem and image of the person with AD. Strategies such as minimising their awareness of their failing abilities and maximising the extent to which they still perceived themselves independent and useful were used by most of the relatives interviewed. They sought to this in a number of ways, such as:

- enabling him or her to maintain certain responsibilities and hobbies, such as managing the family finances:

> ***Anne:*** *In my case I say: 'I'll check what he pays and what he does, but without taking over. That would be terrible for him.*
>
> **The Armendariz Family (2)**

- keeping the person active and in contact with other people:

> ***Carla:*** *I live with her 24 hours a day. I care that she is tidy, that she continue with her routines… We do a lot of things, reading, writing booklets... She has a book with exercises from the memory unit program and she does them every day. We go for a walk every day. I care she meet people to go to the social club, to play naipes. Despite she forgets everyday how to play naipes she goes there, just to meet people, to chat a little bit... and thus she feels alright.*
>
> **The Cervera Family (2)**

- Enabling the person to continue doing meaningful activities:

> ***David:*** *Denia, my cousin, has a daughter who lived in Tarragona and now she is living here. She will stay here for a while and then, the other day she came to visit my mother and she said to her: 'why do not you make a painting for me?' Then they are now doing that. Yesterday my mother suddenly remembered it and said 'Denia's daughter told me if I could paint something for her', 'Oh, fantastic!'. You know, this is more about pretending she makes something that she enjoys rather than the painting itself…*
>
> **The Dominguez Family (2)**

Minimising the awareness of the person's failing abilities and their memory loss were usual practices among family members. The following quote, taken from an interview with David, a son caring for his mother, captures the protective attitude he adopted by not sharing the diagnosis with his mother and downplaying the significance of her forgetfulness:

> ***Nuria:*** *How you think your mother feels about the condition?*
>
> ***David:*** *She, on one hand, she is not really aware of having AD so...*
>
> ***Nuria:*** *She doesn't know it, does she?*
>
> ***David:*** *No, she does not. But she notices she forgets things because she repeats many times: 'Aw shit! I do not know why I`ve forgotten this'. For example, the times I ask her: 'What have you eaten for lunch?' She says: 'why have I forgotten it? I do not remember it!' This is what she says; but she is not fully aware of the condition. She has never said 'I have this disease'. Then in that sense she is pretty docile. For example, when she attended the memory unit programme three months ago, she noticed she had loss of memory but, you might say to her things such as: 'this is to help your memory skills improve'. Regarding medication for instance, she takes the medicines as if these were a support for her memory skills rather than as a treatment for her condition. I do not think she is aware of the condition.*
>
> ***Nuria:*** *Then I understand that you have not shared it with her, have you?*
>
> ***David:*** *No, no. I haven't said it to her directly. Because I consider that way might be harder for her. Sometimes I even tell her 'I also forget things Mom' and I try to downplay what she has to avoid her feeling depressed. Sometimes she says things like: 'I wish to die!' Then, I think this way she suffers less than… (The son showed he was emotionally affected)*
>
> ***Nuria:*** *So you refer to 'memory loss' when you converse with her.*
>
> ***David:*** *Yeah, that's it, memory loss.*
>
> ***Nuria:*** *During our first encounter together you called it forgetfulness, yeah.*
>
> ***David:*** *Yeah. She feels this way and I think, perhaps I am wrong, but I think this is better than saying to her 'Hey mom, you have AD'.*
>
> **The Dominguez Family (2)**

This protective dimension of care was also the subject of debate during the focus groups. The participants focussed in particular on whether or not sharing the diagnosis with the person with AD was a justified and was a strategy to be adopted by the family. They provided a detailed account of why they did not tell the person he or she had AD:

> ***Inma****: I've not say it to her… what could you gain telling her that? You have AD; alright, you forget certain things.*
> ***Idoia****: I think that my mother did not want to know it because she always said..., she is 90, but since she was in her seventies she has always said: 'Losing my head would be terrible'. She could not think of losing her head; that was the last thing in life for her. She said: 'I prefer being in wheelchair before losing my head, this would be the last'.'*
> ***Ilda:*** *In my opinion, this would have been stupid. Mostly because to cope with cancer you have to be strong, but for what reason I should tell someone who is 'out of her mind': 'Mom, you know what? You have AD. Then she would have got sad and I would have felt worst. On top of losing her mind, why does she have to feel sad? What is more, I could not hear the word 'Alzheimer' on the TV while I was with my mother. I tried to avoid it as much as possible. I hid the books, the guides I have. I've never opened a document that includes the word 'Alzheimer' if my mother was present.*
> ***Nuria:*** *what motivated you to act this way… your mother, yourself?*
> ***Ilda:*** *I guess myself. Because I know my mother does not care about it, but at the beginning I did not know if she cared or not about it. So I decided she had to continue like that. She has already suffered enough throughout her life to give her that shock.*
>
> **FG.1**

> ***Lucas:*** *I talked to her from the beginning. Right away I got the diagnosis. I did not talk to my children. I just talked to her. I said to her: 'let's see love, now we have a problem; you are not the problem but your condition. So I just want you work with me and together we will deal with it. We will deal with it as better as we can, but please work with me, work with me. You have to worry about nothing. I will cook; I will do the laundry...' (She started laughing) Me! The one who*

> *bragged about not knowing how the washing machine was turned on! 'You do not have to worry about anything love, about anything'.*
>
> **FG.3**

Some relatives argued that it would not be sensible to tell their relative the nature of the condition as they did not want to cause distress to the relative and preferred to carry the burden of that knowledge alone. Others were afraid of the effect that the diagnosis would have on the person, so they decided not to tell him/her, just in case. As it was difficult to be sure if the person wanted to or not the default position most relative took was that it was better not to tell them. Of course, as already noted, the effect of this was to remove the person with AD from a position of knowledge and some control, with most things being progressively been taken out of their hands. This is something that will be discussed more fully later. As the disease began to progress it was clear to most families that things were changing and their response was to start to *'redefine'* a number of roles and relationships.

'Redefining'

As families continued to recount their experiences of living with AD it was clear that as the condition slowly progressed that a turning point in the lives of the participants was occurring. This, for most and in several different ways, entailed a fundamental shift in the meaning, purpose and direction of their lives which challenged well established ways of family functioning and compelled its members to consider how they wanted to live henceforth and where they wanted to make commitments.

It was by the process of 'watching' that people became aware of the changes that were taking place in their relatives and therefore in the whole family. Data suggested that this realisation of *'our life is changing'* led the families to 'redefine' certain aspects of life and thus readjust to the new family situation. AD posed challenges to every member of the family as well as to the family as a group. The following response from the Armendariz family provided in response to the question '*What does AD mean to the family?'* captures the changes that AD had brought for them:

> ***Anne:*** *I understand that my life has changed*
> ***Abel:*** *Everyone changes, doesn’t it?*
> ***Anne:*** *You see that?*
> ***Adela:*** *Well, things are moving on, aren’t they?*
> ***Abel:*** *Things evolve*
> ***Adela:*** *Then, when there is such alteration everything moves around it, everything!*
> ***Anne:*** *Of course! This changes your life.*
>
> **The Armendariz Family (1)**

The above words offered by Anna and Adela, *‘everything moves around it’* and *‘this changes your life’*, highlight the central shift in different spheres of life for individuals and the family as a unit. Until the onset of AD this family had maintained quite stable patterns of function and interaction; its life had run quite smoothly adapting to situations as they arose. However the change in the health status of Abel proved to be a vital transition for them. In one way or another this was the case for all the families as the following quotes from early interviews attest:

- *'This is a big change’* (The Blasco Family)
- *'Our life has changed as well’* (The Cervera Family)
- *‘Everything changes a little’* (The Dominguez Family)
- *‘Obviously, our life is changing’* (The Estevez Family)
- *‘Now, everything is different’* (The Gonzalez Family)
- *‘There has been changes, and these changes hurt a little’* (The Jimenez Family)

Although they were not able to alter the condition itself families were able to elaborate on the ways their lives were redefined after its onset. In this study the ‘redefining’ process resulted in the creation of new patterns from existing components of family life, chiefly in family roles, responsibilities and relationships, everyday life routines and the vision for future that the families held. Each of these is addressed below.

Redefining Roles and Responsibilities

The families in the study tended to be organized in terms of roles, as they described during the interviews. In many families members knew the responsibilities each one assumed such as who did housework, who provided emotional support, who handled the finances and so on. In these circumstances there was clarity and agreement about these ‘implicit’ roles before the onset of AD; however afterwards some of these need to be ‘redefined’. As noted in the case studies it was often at this point that difficulties arose.

How roles and responsibilities were redefined was influenced by many factors such as family background, family composition, previous ways of working and particular characteristics of each member. For instance, in families where the couple still remained together, the spouse of the person with AD tended to gradually assume the roles and responsibilities that had been their partner’s before the onset of AD, often in addition to other caregiving responsibilities. In these circumstances the rest of the family (largely children) played a more supportive role and helped the spouse in taking on new those responsibilities. This was the case with the Armendariz, the Cervera and the Jimenez families, in which the couple still remained together. Here the supporting role of children is very apparent:

> ***Anne:*** *I have never cared about things related to banks*
> ***Adela:*** *In that sense now she cares more about it, doesn´t she?*
> ***Anne:*** *I’ve always worked at home, you know? And he managed the finances*
> ***Adela:*** *I use to explain her how she has to connect to the internet and such things. She does it perfectly (...). My father has always managed the finances. They had several rentals and such. So he has always managed everything. Now, my mother has to keep track of this.*
> ***Anne:*** *That is what I have to do.*
>
> **The Armendariz Family (1)**

In the case of the Cervera family it was immediately assumed that Carlos, the husband, would care for his wife with AD. Although this occurred quite naturally their daughters helped and support their parents considerably. Thus the daughters assumed the additional, and hidden, responsibility of *'keeping an eye on'* their parents, as well as providing some direct support. From their accounts it was clear that the support daughters provided to Carlos reduced the demands he faced and enabled him to feel relaxed and supported in his new role as a carer:

> ***Cecilia:*** *Today my father is the one who is alright.*
> ***Camila:*** *Now he is the one who is here, with her.*
> ***Cecilia:*** *And the one who has to care for my mother. We have children and we have our lives. Although we try to help them as much as we can.*
> ***Carlos:*** *They are here everyday*
> ***Cecilia:*** *We are dealing with this situation for almost nine months, nine months! And we are with them day after day.*
> ***Carlos:*** *Everyday!*
> ***Cecilia:*** *Then, our life has also changed a lot.*
> ***Camila:*** *Every single day! We're here for any problems they may have. Living 40 kilometres away or living just 5 minutes walking is not the same; you know that!*
> ***Cecilia:*** *Then… naturally they are alright but because we've helped them to change for the better, you know what I mean? For example now I see my father is happier. Because he was conscious of the responsibilities that were coming to him and in this sense he now.. he feels fully supported. This has changed our lives but if they are alright…*
> ***Carlos:*** *Here we have a completely different life.*
> ***Cecilia:*** *Yes, they do.*
> ***Carlos:*** *Totally different! They come here every day, every morning. They help her in bathing. They clean the house. Many days we go for coffee all together, we take a walk and so on…*
> ***Cecilia****: And after doing all of that, we run home quickly to do our*

> *housework. In the afternoon…, afternoons are different.*
>
> ***Camila**: Yeah, we don't come in the afternoon*
>
> **The Cervera Family (1)**

From the above family account it was clear that the support Carlos received from his daughters was essential to making caregiving a more positive experience. The new responsibilities and roles of the daughters as guardians of their parents entailed them organizing their own daily life routines (assisting their parents during the morning, while taking care of their own family in the afternoon). However the fact all of them were involved in caregiving and wanted to do this, allowed the family to consider caring as a responsibility but not a burden.

Not surprisingly Carlos' death was a turning point for the Cervera family, and compelled the family to redefine roles and responsibilities within the group, especially in relation to Carmen's care. In this instance Carla was the one who assumed the major responsibility for her mother's care. However this was agreed by all and did not cause difficulties in family relationships. Carla had always assumed a leadership role in the family, especially in difficult circumstances. Therefore the onset of AD, as a critical event for them, followed the same pattern as previous family experiences:

> ***Carla**: This situation is the same as the one in which my father suffered from cancer and I decided to take care of him. I mean, it (caring) has always being my role within the family. The same situation when my brother died. Then, I have always had to handle these situations. Because my older sister, she has always been in the background, you know what I mean? I mean, she is present but at the same time she is not.*
>
> **The Cervera Family (2)**

Changing roles did not only affect those members of the family that assumed new task and responsibilities but also the person with AD who now often gave up the roles and responsibilities that had always been his/hers. The quote below for example, describes the impact of this on Justina, the person with AD, and her family. Justina had always taken care of the rest of the family and moving from being the ‘carer’ of the family to being the ‘person subject of care’ was far from being an easy experience. She felt she was losing the role that she had always had within the family; a role that somehow defined her identity within the group. Consequently, role swapping required time for the family to adapt and make sense to the new shape the family was adopting. Her husband also found the changes quite a challenge.

> ***Julieta:*** *Yeah, but this happens because she does not want that our dad helps her. And ‘this’ has to be like she says.*
> ***Justina:*** *if I can do it, why do I need help?*
> ***Julieta:*** *But dad knows how to do many things. He can prepare them as well.*
> ***Jimena:*** *He has never ever done it so he is not going to do it now.*
> ***Justina:*** *I do know why he has to do it.*
> ***Julieta:*** *Yeah, but…*
> ***Jimena:*** *Don’t forget that Mom has always told Dad how he should dress.*
> ***Julieta:*** *Yes, but now it is time he…*
> ***Jimena:*** *But this change hurts. From having someone that told you what cloths you might wear, that gave him everything done to…*
> **Nuria:** *the roles have changed a bit, haven’t they?*
> ***Jimena:*** *Yes. This change is being difficult to both sides. My father is the classic man, the one who has ever done nothing. And today he is the one who takes care of her, her medication… their roles have been exchanged and that is complex for everyone. Firstly for her and then, for all of us who are close to her. This change is a huge one!*
> ***Justina:*** *From doing nothing to now doing many things.*
> ***Julieta:*** *But there is no problem in that he does something*
> ***Jimena:*** *Of course there is not any problem. But this change hurts everyone*
> ***Justina:****Yeah!*
> ***Jimena:*** *Changes hurt!*
>
> **The Jimenez Family (1)**

Justina's identity was intrinsically linked to and influenced by the commitment she had to the family. Thus the role change she experienced altered the mother-daughter(s) relationship that has always existed, something that was a loss to them:

> ***Jimena:*** *This is as grief in life; this is how I call it. She is alive but you're living, you're living a loss, as if she had died as if… because you are losing your mother.*
>
> **The Jimenez Family (2)**

By contrast, for the Gonzalez family in which Gabriel, the person with AD, did not have such a prominent role in the family, redefining roles seemed to be less painful. Therefore the experience of losing his role had relatively little impact on family interactions.

> ***Nuria:*** *What about the role that Gabriel played in the family, has it changed?*
> ***Gemma:*** *Not at all. The change is that now we care for him. He continues doing the same things as usual. He has never done anything at home, and he continues doing nothing. He has never ever cared about the financial issues and such thing. My mother cared about it. She was who care about everything at home then…*
>
> **The Gonzalez Family (2)**

As it is clear from the above roles and responsibilities in such situations were mostly assigned and assumed by the spouse, since this was the expectation of the family. By contrast, in families where there was no partner, children and significant others had to decide and organize the ways in which new roles and responsibilities were divided and shared within the family. Here children and significant others had to take a lead. In some instances reaching agreement about organizing care was challenging and could result in family conflict and low levels of satisfaction, as it was the case of the Dominguez, the Gonzalez and the Jimenez families.

Sometimes perceptions of the situation amongst different family members varied and this could cause disagreement about who should take on care responsibilities.

> **David:** *My sister says my mom has nothing (wrong with her), that she is fine. My sister opinion is completely different (to mine). She does not want to know anything. Then she denies it and she does nothing.*
>
> **The Dominguez Family (2)**

At other times, although there was active participation among the family members involved this did not meet everyone's expectations, and one member often assumed the major responsibility. For instance in the Gonzalez family, even though the two sisters managed to care for Gabriel, their father, there was no real agreement on how these responsibilities should develop over time. Thus Gemma tended to assumed more responsibilities, producing a perceived imbalance and conflict between the sisters. The following quote illustrates this and also illustrates how some outside help would have been appreciated:

> **Gemma:** *If someone could advise us: 'look you are going to find these kind of troubles. Then, what most people usually do is that one member takes control of medication, the other one cares about this, the other…' We need to organize! Then if someone from outside explains this to us... Given that I cannot say anything (to my sister) because then I am ordering. It is too easy to label someone, and since I don't like anyone to tell me: 'you are a bossy', then I say nothing. I say nothing and I am still being a bossy; it is too easy… I already told my sister: 'please, organize this as you want'. My sister has never told me: 'Gemma, you have to do this. I will do that'. I have never heard (from her): 'I am going to do this and that and you may' do this and that`.*
>
> **The Gonzalez Family (2)**

The above quotation suggested that the family failed in redefining roles and responsibilities without it affecting family relationships. Organizing and reaching agreements was a very difficult task and even Gemma suggested the need for professional support to help them with this *('if someone could advise us…').*

Similarly, during my second interview with the Jimenez family daughters, they acknowledged their need to discuss and agree responsibilities and roles within the family. But they also highlighted how the situation had exceeded their abilities to reach agreement and that this had resulted in conflict:

> ***Nuria**: What's your major concern at this moment?*
> ***Jimena:** Organizing between us. I'm afraid that, because we are pouring over each other our discomfort… we just fight instead of working together to solve things….. we are doing that, confronting each other instead of resolving… We are not resolving this situation. Then, if we continue this way…! I think: 'It's perfect! (Ironic tone), we are getting angry each other. Then instead of working to get solutions and seeing what we can do, we are worrying about who does more than the other one, you do more than me and you should do more about…'. Then this is a matter of recognizing how each one can contribute and thus organizing this situation; because it is getting more complex and we just argue.*
>
> **The Jimenez Family (2)**

In our last encounter this situation, far from changing for the better, had become worse. As Jimena explained her family was in need of support to help them to resolve these conflicts.

> ***Jimena:** I was coming here thinking on that, even asking you where can we go to have more information about the disease and help us, because it is something that we need… we have no information, we do not know how to manage our conflicts… then, there are a lot of things. Then we think we've reached a point in which we all need professional help.*
>
> **The Jimenez Family (4)**

The process of ‘redefining’ was clearly challenging for some families, while others were better able to talk things through and to agree what they saw as a fair share of responsibilities. This was the case with the Estevez family. Below, Elisa gives account on how she and her five siblings shared responsibilities in taking care of her mother with AD. They agreed that she cared for her mother during the week, as she was the one who lived closest, while the rest of her siblings took turns to look after their mother during the weekend:

> ***Elisa:*** *My God! Organizing with my brothers…, this was a big deal. Because for example, the case of my brother who lives in Lugo (500 km away from home) and he came every weekend from there… He has 5 children and one of them is a teenager girl then… One day he said: ‘Help! I cannot deal with everything!’ Then we all talked to each other and said: ‘let’s see how we all can handle this’ and then they (the rest of my brothers) reorganized themselves. I told them: ‘I just want to know who is coming on the weekend, I do not care how’. Because if I care that one of them has this, the other one has that… I cannot do it! My oldest sister organizes all of them and she tells me who is coming on Friday. You cannot imagine what a mess it would be if I’d have to worry about that… no way, no way! I clearly said to them: ‘I only need to know who is coming to take over my place; that´s all’. Thus we decided to work in this way: my oldest sister organizes who has to come on the weekends and then I leave my place.*
>
> **The Estevez Family (1)**

Although everyone had a role in caregiving and all of them assumed certain responsibilities, there was still a particular member of the family that assumed greater responsibilities in care. Nevertheless the support Elisa received from the rest of the family was crucial to her accepting and coping with the situation. She, despite having to deal with more care activities, saw her brothers as a major source of support to:

> **Elisa:** *We are currently organized well. Fortunately, thank God I have five siblings. If I had not had them I'd have died... Now I understand why some families rely on nursing-home care.*
>
> **The Estevez Family (3)**

Clearly the way in which families redefined their roles and responsibilities did not follow a set pattern and what worked well for one would not necessarily be useful to another. However it was clear that some families managed this 'redefining' more successfully than others and as the case studies in the last chapter showed this often influenced the way in which the family dynamics responded to the presence of AD. It also impacted on the ways in which roles were redefined in everyday life.

Redefining Everyday Life

Changing roles and assuming new responsibilities, including caregiving, required family members to reorganize aspects of their everyday life; for instance prioritizing daily activities, altering and rearranging daily schedules and even moving to another house. Adela, who helped her mother to care for her father with AD gave an account of how she organized her daily activities to support her parents while maintaining other aspects of her life. Giving a hand in caregiving (a new responsibility for her) meant that she had to reschedule her week and to find time to do everything. Flexibility and commitment were required so that she could get involved in care activities without giving up her other roles, responsibilities and future plans.

> **Adela:** *The thing is that I am currently here and I can be with them (my parents). In that sense I think that my brother, that lives abroad, feels more relaxed. He feels more relaxed because he knows perfectly well that I'm here and that I come every afternoon. I try not to come so much during weekends to also maintain my family life.*
>
> **Nuria:** *So you try to continue your life as far as possible, do you?*
>
> **Adela:** *Yeah, yeah. I mean, I come every afternoon. I used to come to have lunch with them (my parents). But we (me and my husband) are now preparing a project and my husband works at home.*

> **Abel:** *She said that he is unemployed but he is not.*
>
> **Adela:** *Yes, we are unemployed but we are currently working on this. We are developing a project. We are quite optimistic, we are happy… And then of course I like having lunch with my husband. So what I do is to pick up my kids from the school and then I come here (to my parents' house). I'm working in the morning and also at night, once my kids go to sleep. Then this is how I organize my day to being with my kids, helping them doing their homework… I mean, continuing my life with an order and taking care of them (my parents) as well.*
>
> **The Armendariz Family (1)**

While in the above case redefining everyday life, particularly rescheduling daily activities, seemed to be an acceptable compromise, this was not so easy for all the families. Sometimes caregiving presented conflicting demands and family members had to set priorities and withdraw from activities that were important for them. This could create feelings of *'losing freedom*' and create a disconnection with what they had or used to do before the onset of AD:

> **David:** *This prevents me from doing things. For example, you know I used to go to for a motorbike ride whenever I wanted; now I cannot do this kind of things because I have to be with her in the afternoon.*
>
> **The Dominguez Family (2)**

> **Blanca:** *This is how I feel. This is constraining my life. For example now that I want to go to my village to spend my Easter holydays… I've been thinking: 'if we're going to the village, how long we'll be able to stay there? If I have to be with her (my mother)…' Because if something comes up and she (her sister) cannot help her with it because she is with her kids… Besides, you feel a little, you feel almost guilty, don't you? Like If you were away and then you left her here. Also, if we have to do some paperwork and you cannot go and then my sister has to go, you feel a little wicked, as if I…*
>
> **The Blasco Family (1)**

Not surprisingly moving to another house proved to have a major impact on the everyday life of families. It required them to abandon or modify past routines, whilst at the same time creating new ones.

> **Elisa:** *You see that this situation is pretty good now but we had to organize, and that was...!! Getting organized was too much; it was too complex. Moving to another house, Oh God! That hurt me a lot.*
>
> **The Estevez Family (1)**

Even those who had not left their homes yet (or in which their parent had not move in with them) recognised that this might be needed, and this was seen as a difficult decision, as the following quotes illustrates:

> **Bea:** *Let's see, you had your life organized and now, as my sister has said, you have to reorganize it to take care of her. We've already understood that we have to go to the doctor with her almost every week…*
>
> **Blanca:** *Also I see that, particularly my fear is that… we've been dealing with this through the memory unit so far but this is getting to the end and my mother is getting worse. Then the problem will come if we have to bring her to our home. There will be a time in which she will be unable to stay alone, to cook or do anything, because she could leave the gas on. Then, bringing her to our house, bringing her forcibly, because she does not want to come… Living with her will be something…*
>
> **Bea:** *Unthinkable!*
>
> **Blanca:** *My fear now comes because I have children, I have a family… How am I supposed to keep that?*
>
> **The Blasco Family (1)**

> **David:** *Let's see. I see, from my point of view of course, I feel that we will reach a time in which I will have to move to my mother´s house and that will mean ruining my life. I do not know if you understand me. I will lose all my independence, my autonomy… The problem is that*

> *having not enough money to pay for a caregiver will mean us moving to her by force.*
>
> **The Dominguez Family (2)**

On the other hand moving to a child's house was not necessarily easy for the person with AD:

> ***Carmen:*** *I'm living in my daughter's home so I am living completely different (…)! I'm living in my daughter's house. I am alright but this is not my house. Saying this I am telling you everything. You understand? If my daughter tells me 'this' then it will be 'this'; if she tells me 'mom, dance' then I will dance. As far as I am living with her, everything she tells me, everything I'll do.*
>
> **The Cervera Family (3)**

Intergenerational living was not a decision to be taken lightly and this, as well as other changes brought about by caring could impact on relationships, which also often needed to be redefined.

Redefining Family Relationships

As has been noted changes in the person with AD and the need to redefine roles could also impact on family relationship, which also had to be redefined, both with the person with AD and other family members. Below Gemma describes her new relationship with her father Gabriel and how he no longer seemed to acknowledge the needs of others:

> ***Gemma:*** *I've noticed he has like 'ups and downs'. During our holydays there were few days he was with my husband and he spoke nothing to him. We did three miles walking on the beach and he did not speak to me; he did not speak. One day, when we were walking on the beach, I stepped on a bee and he continued walking as if nothing had happened. Then I said to him: 'Dad, come on!' and he answered me: 'I have already stop for a while'. I said: 'yes, of course!'*

> *(Ironic tone) He just stopped listening to me and that was all. He did not care about how I was.*
>
> **The Gonzalez Family (2)**

As a consequence of his changing behaviour Gemma became more distanced from him:

> ***Gemma:*** *I see my father is now more aggressive with me. This is... OMG! I do not know! Perhaps he feels worse. I do not know why. No, no, no, no, no. I do not understand, I do not understand. That is like if I had emotionally distanced from him. I mean, I'm going to care for him, doing the same, as I've done so far but... no, no, becoming more distant.*
>
> **The Gonzalez Family (2)**

Similarly Julieta's relations became complicated as a result of the changing behaviours Justina, her mother, now displayed. For Julieta, who had always been close to her mother, this was very difficult to accept. She recognized that her mother was not behaving like this deliberately but she still reacted angrily and then felt guilty for doing so:

> ***Julieta:*** *I get upset because now I argue with her more often. I know she would not disrespect me if she was conscious of it. I know that; but I react by getting annoyed and I think: 'My reaction was very poor; I finally did what she wanted; and this is precisely what I do not have to do'. Then I think: 'I've done wrong'. This is what I think. Because anything she may say to me does not affect me at all, because she is not conscious of what she is saying to me. I believe she is not conscious at all so that does not affect me. But my reactions are wrong; I think myself: 'My reaction was terrible; I should not have quarrelled with her!'*
>
> **The Jimenez Family (2)**

Jimena, her sister, also pointed out how the symptoms her mother displayed were altering family relationships, and not just with her mother.

> **Jimena:** *this is affecting all levels of our family relationships because my father complains about everything. My mother does things we do not understand, no one does. We try to find the logic to that but there is no logic and as a result my father gets desperate. Then, there are times that even we get upset with her and we tell her that so she also gets upset. For that reason we discuss to each other many times; we discuss because she does something that has no sense to us.*

When situations like this occurred it was common for relatives to try and get the person with AD to change their behaviour. However this usually did not work and led to more frustration, further compromising relationships.

As already noted changing roles also required redefining relationships and new patterns of negotiation and communication had to be forged. If these were successful then relationships could be enhanced, if they were not then sometimes complete family rupture occurred as described in the case studies in the previous chapter. From the experiences of the family participants it was clear that caring impacted on family relationships. For some caregiving worked as a unifying element and improved family relationships, as was the case for the Armendariz family and to a lesser degree for the Belasco family. While for others, the constant disagreements about care altered family relationships for the worse, as for example in the Dominguez, the Gonzalez and the Jimenez families.

The significant effect that family relationships had on the overall care experience was also commented on by participants in the focus groups. As with the main families for some of them caregiving served to strengthening family ties, for others this was an evident source of conflict.

> **Marta:** *Before, there was little contact among us; now there is nothing, little or nothing. I have little contact with my sister and just via mobile phone. And this is a constant fight.*
> **Maddie:** *By email...*
> **Marta***: It's a constant fight... (She exemplified a particular disagreement with his sister). We only argue each other, now! Pum! I do not have any problem with my two brothers. But the relationship*

> *with my sister is... wrong, wrong, wrong. Because we are not four in the family, we are three. This is as I am telling you.*
>
> **Maria:** *Well, I have to tell you all the other side. Before, we had lot of problems in the family; they were largely due to my parent's personality. So we had lost ... well I lost my older sister. She moved to another place. The relationship she had with my parents was so difficult that she had to go away. She did not tell anyone where she went. Then we lived very hard years. I have been receiving Psychiatric treatment for ten years (she started to cry). I am sorry (…) Then now I perceive this as the 'disease of love'. In the end the affection is the last thing they lose, isn't it? As I have already said we are living the opposite side. The Alzheimer's dissipated the negative face of my mother. Furthermore, the first sign we noticed was my mother gave us lot of hugs and kissed, she showed lot of love to us. Then, that kind of behaviours in someone who has always been quite the opposite... Thus, this is a disease that me and my family welcomed as something marvellous, such bless! Such a treat! This has brought all of us together.*
>
> **FG.3**

The testimony of the following daughter describes how the impact of caring is often a result of prior relationships in the family. She explained how her family went through times of tension and conflict and but they were able to resolve these; she firmly believed that this was due to the relationships that they had had before AD and the way that they worked as a family.

> **Isabel:** *So far our relationships have not changed. But I also consider that we're special. My sisters are really involved in this. We all agree in that we have to be here'. People always tell me that we are going to end up arguing each other. I think that we are currently alright. Although we have had some periods in which... there has been disagreements on how to react and on how to understand the situation. Then we've gotten distant, but little by little we've resolved the tensions. Hence I hate when people say to me 'you will see, but you will end up distant from each other'. I hope that, taking into account how we all are and the education our mother provided to us,*

> *that there will be no reason to get distant. I think that the education that my mother provided to us is helping us in living this situation.*
>
> **FG.1**

Creating a Vision for the future

Addressing the impact of AD over time was one of the key challenges families faced. They had to navigate between overcoming the practical and emotional dimensions of living ‘day-to-day’ whilst planning for an uncertain future full of unknown complexities.

For some families their vision of the future was full of anticipatory questions and uneasiness about *‘what may come next?’* This could deplete them of the energy they needed to plan for the future in a proactive fashion and inhibit how they dealt with present challenges. Conversely other families were able to put the (uncertain) future into perspective and to remain positive and hopeful, looking ahead to what they might face rather than being fearful. These families were more likely to adopt a proactive attitude to the care experience and to concentrate their efforts on doing their best day-to-day. Family dynamics played a key role in shaping these perceptions.

Families ‘living in fear of future’ expressed profound concerns in relation to both the progress of the condition and the implications it might have for them and their own lives. The words of the following son capture concerns both for his mother’s future and his own:

> ***David:*** *I see my mother is not going better, then logically… on one hand, I do not want my mother die, but on the other hand I do not know what would be better. Because I say myself: ‘if she continues like that… how is this going to end?’ I know how people with AD my end up. I know people who have their parents living the same situation; specifically the wife of one of my friends; her mother is so deteriorated; she can no longer speak, she doesn’t even eat. So I do not want my mother to go through that situation. I’d prefer she dies before getting into that. However I also wonder: ‘how about if she is*

> *like her (mothers' friend)?' Certainly, she is not going to be as she is at present and finally she will need someone to be with her. My sister does not want to be with her so I can guess what is coming. I know I am anticipating events but… I just think 'if this happen…' I worry about everything. On one hand, how I will see my mother in future, on the other hand, how this will affect me, how am I supposed to handle this situation? I do not have enough money so I will have to live with her. My sister does not want to do anything then… Living with someone with 'this' (AD) is going to be terrible. The situation is going to be terrible.*
>
> **The Dominguez Family (2)**

The feeling of 'living in fear of future' was often a facet of existing poor relationships within the family which affected the level of involvement of its members. This was clear in the case of the Dominguez family. Similarly, if the care experience was governed by a sense of duty, as it was other families then constant concerns about *'what might come next'* dominated their thoughts.

Concerns about the future were understandably more prevalent in families where there were constant disagreements about caring decisions and the sharing of responsibilities, as it was unclear who, if anyone, would assume a lead role. This was the case for Gonzalez family. In our final encounter Gemma voiced the concerns she had about the increasing future demands caring for her father would bring. As her family could not agree on a way forward she felt that inevitably the role would fall to her and her own life would be significantly compromised.

> ***Nuria:*** *What would you say is what you are most concerned about at the moment?*
> ***Gemma:*** *That I see it may be very difficult to stay with him at home quite soon. It may be very difficult, very hard! Because now I feel that I have no freedom, if now I feel that way... I have to help him to dress, I have to help him to bath, he wakes up constantly at night and when he gets up he disorganizes everything, everything. Then I say, Oh God! How we are going to organize? That's what, what really bother*

> *me. I have some ideas of… but, but I say 'no, no, no, no, that is not…' I perceived that more responsibilities (work) are coming over us, and especially to me. I can foresee it. Because, because my sister is there and yeah… even if we have someone who takes care of him, even if we have five (people)… Those people need to be organized and you have to control them. That's the point.*
>
> **The Gonzalez Family (2)**

On the other hand other families preferred living day-to-day. Potential future, and as yet unknown, changes were not regarded as a threat but rather as a challenge for the family. Thus its members strongly believed in the need to focus on the present and do their best day-by-day.

> ***Adela:*** *I think we have to think about the day-to-day*
> ***Abel:*** *The day-to-day*
> ***Anne:*** *Our present. Doing the best we can, doing everything we can. Because if you start thinking what's going to come next…!*
> ***Adela:*** *Yeah*
> ***Anne:*** *When things come…*
> ***Adela:*** *I think you have to deal with things as they come*
> ***Anne:*** *Yeah, exactly!*
> ***Adela:*** *if you just think on 'if, if, what if…, if this happen…', then you do not live, don't you?*
> ***Anne****: 'if, if…' (She hit the table) Look to the present and do whatever you can!*
>
> **The Armendariz Family (1)**

During the individual interviews with the caring wife it was clear that the families' religious faith was important in shaping their approach to the future, which was seen to lie largely in God's hands:

> ***Anne:*** *While we can go on, we will go ahead! When we cannot do it, God will open our way. We have to do whatever we can and adapt to it by saying: 'you have to pull forward'…*
>
> **The Armendariz Family (2)**

As well as family values close relationships among members of the family and a high level of emotional involvement in care meant that such families tended to make the most of the present rather than being too concerned about what the future might hold:

> ***Jimena:*** *the only certainty I have is that this is going to get worse.*
> ***Julieta:*** *Yes, we have the same feeling.*
> ***Jimena:*** *Then rather than feeling uncertain, I know this is going to get worse. Then we have to take advantage of the present situation.*
> ***Julieta:*** *This is what matters.*
>
> **The Jimenez Family (4)**

The focus group participants reflected similar thoughts. While some caregivers advocated living day-to-day, believing that this made their experience more bearable, others could not avoid thinking about the future and the progress of the condition:

> ***Lucas****: If you have this philosophy (‘what if.., what if…`) you are completely lost. Dammit! You have to live for the present!*
> ***Leonor:*** *Yeah I know. I say myself: ‘I’m going to live in the present’. But then I stop and think: ‘this is getting worse, would I be psychologically prepared for…, could I handle…?’ I mean, it is unavoidable to think we’re getting worse. I mean, as you´ve already mentioned: ‘every step you take is not going to make it better’. Then I see it as unavoidable to think such things. I often say to myself: ‘I am going to live in the present and I am not going to brood over it’ but to be honest I also think ‘Oh my God’!*
> ***Lucas:*** *You do not have to anticipate events.*
> ***Leonor:*** *Yeah, I know it. I am not anticipating but… puff! You have it here.*
> ***Laura:*** *Yeah, but this is not worth it. Because sometimes you may say: ‘in this situation I am going to do this and this’. Then what you have foreseen does not take place and something to which you are*

> *not prepared for comes out. So, it is better to solve things as they come, otherwise you´ll get exhausted.*
>
> **FG.2**

Interestingly the more experienced families who had lived with AD longer, showed a more serene attitude towards future challenges than those who were relatively new to caring.

Overall both ‘redefining’ life and thinking (or not) of the future was fairly bearable for families who worked together, even though they experienced stress largely due to the changes and losses they saw in their relative. By contrast, other families struggled to deal with tensions which emerged as a result of constant disagreements, even if they faced similar objective circumstances to other families. Where families could not resolve current disagreements the future understandably looked worse and they became drained of strength and energy. This prevented them from finding any satisfactions in caregiving and it was more difficult for them to *‘keep things together’*.

6.3 *‘Keeping things together’*: The importance of ‘balancing’

As I became more immersed in data collection and analysis and with on-going contact with families I sensed that all of them were, to a greater or lesser extent, wanting to try and *‘keep things together’* in the face of uncertain and constantly evolving challenges. Families faced the formidable challenge of focusing simultaneously on providing the best care possible to the relative with AD and at the same time trying to preserve the personal, social and working life of the family. As their lives were constantly changing family members strove to maintain a balance between the demands and the resources they had to both provide care and preserve the wider family. To do these families were constantly adapting, changing and responding to daily events. As might be expected from the family case studies some participants were able to do so more effectively than others, who began to *‘fall apart’*.

Building on this interpretation the process of ‘balancing’ emerged as the basic social process (BSP) that shaped the lives of families living with AD. It was identified as a fundamental process in the behaviours and responses of families to AD. It occurred over time but with varying degrees of success in all families. It had a cyclical and temporal relationship with prior processes that tend to re-occur in response to new challenges.

In trying to achieve balance a certain degree of conflict was found amongst all families, but, as already noted, some were better at resolving conflict and *‘keeping things together’* than others. For families with poor prior relationships, where disagreements and conflicts pre-dated the onset of AD, and care was largely duty-driven *‘keeping things together’* proved very difficult. Previously close relationships and patterns of communication that provided ways of talking things through acted as stabilizing and protective factors. However, as the case studies showed disagreements about care could destabilize family dynamics transforming closeness to conflict, thereby increasing stress and suffering, and causing imbalance in the family.

Once again these families who could reach agreement and work together were better able to achieve the balance required. The Armendariz and the Estevez families, for instance, were a clear example of this. They were able to combine caring with other important aspects of their life such as working, leisure and so on. Thus they evolved and grew as a family. In other instances families wanted things to remain as they were and found it difficult, if not impossible, to agree on a way forward. They invested heavily in caring (which was perceived as a difficulty) but conflict was the primary dynamic. This was clearly the case for the Dominguez, Gonzalez and Jimenez families.

The outcome of the caring experience varied depending upon which ‘balancing’ pattern the family developed.

Achieving Care-Family Balance

‘Care-family balance’ suggested a positive relationship between caring and family life. In this case both of activities were viewed as compatible and in balance with each other. An example of this was the Armendariz Family. Although they lived in challenging circumstances, and despite the onset of AD and the care process they were able to maintain usual patterns of family life. Here family members achieved balance by being able to agree how, together, they could exert some control over when, where and how to ‘balance’ time and energy between caring and family life to ensure both remained positive experiences. A clear example of this was the time that Adela explained how she organized things so as to continue with her ‘normal’ family life, helping her children, being with her husband, whilst at the same time caring for her parents and support to her mother Anne.

Despite this Anne had now subordinated her own needs almost entirely to those of her husband with AD and as such there was a degree of imbalance apparent, which had begun to impact negatively on her health:

> ***Anne:*** *(…) I told this to the GP because she noticed that I was a bit nervous. I am not sleeping very well so she recommended me to take some pills… That’s what I’ve told you that I am not dealing very well with it. I am not doing as good as I would like to do it but (…) I wake up every day in the middle of the night (…)*
>
> **The Armendariz Family (2)**

However, despite these difficulties the family as a whole perceived caring as bringing them closer together, and in fact had enhanced the unity and the balance that the family experienced. It had in some way enriched their lives, as Adela noted: *‘this (caring) is helping all of us in some way’*.

Some families were therefore better able to respond positively to the challenges of living with AD and so gain purpose and satisfaction as a result of the care experience. Closeness, a high level of commitment to family and the meaning they attached to their experience were key factors in achieving the necessary balance between providing care without giving up wider family life. However this might not be consistent for all family members. For instance in the Cervera family, despite a lack of closeness within the whole family and deteriorating relationships between certain members, Cecilia’s support for her sister Carla, who had assumed the main responsibility in caring for their mother, enabled her to maintain balance in life. Carla was therefore able to integrate her mother's care without completely sacrificing her own life outside of caring

> ***Cecilia:*** *But, because my mother is living with her (Carla) does not mean that we do not have any responsibility with our mother. You need to take some days off, going on holidays, doing your things… whatever you need!*
> ***Carla:*** *Sometimes I feel.. This is difficult.*
> ***Cecilia:*** *That's why I've said that. My mother is still my mother and you are not the only one who has to work on this. What about us? Are we free of responsibilities? My mother will always be my mother and I have to help my sister.*
>
> **The Cervera Family (5)**

Family growth, the ability to communicate and resolve conflicts, and maintain close family ties and a commitment to the family were all factors that contributed a positive 'care-family balance'.

Apart from family support, having external support resources/services (when available and adequate) could help families to achieve the balance they needed. For instance Elisa, who cared for her mother with AD, explained how there was a time when her mother's care was becoming unsustainable; therefore they decided to make use of day care services. After this their family situation changed for the better (thus regaining balance) and they continued taking care of their mother as usual.

> ***Elisa:*** *We did what we could and as far as we could, and now we continue like this, and this is much better.*
>
> **The Estevez Family (3)**

While for some families it was unthinkable that anyone other than the family should provide care for others external resources such as a day-care centre or a paid-caregiver provided an important resource in maintaining balance. This did not mean these families did not want to take care of their relative, but that they needed assistance to improve their current caring situation.

> ***David:*** *What I see is that… I do not want to spend less time being with my mother but I would like not to have to add extra work. For example the time my mother needs to be with someone, other person could come to stay with her as well.*
>
> **The Dominguez Family (2)**

However, other families found it difficult, if not impossible to attain the necessary 'balance' and in such circumstances caring led to conflict.

Living in Care-Family Conflict

'Care-family conflict' occurred when either implicitly or explicitly families regarded caring and family life as incompatible and competing for time, energy and resources. An example of this was the Gonzalez, the Blasco and the Jimenez families, where the members believed that caring was dominating their lives, and resulting in reduced freedom. Here it was not possible to achieve a balance, conflict arose and such families often had poor prior relationships and saw caring primarily as a duty. Feelings were often ambivalent and conflicting, which spilled over into other aspects of life. The impact of this was worse if it was perceived that other family members were not contributing as fully as they might.

> ***Jimena:*** *I was on vacation for five weeks. I've come back two weeks ago and now I feel terrible. I've noticed I am more serious at work. I argue with people even for absurdities, especially during team-work meetings. The thing is that I just want to discuss with my colleagues. I`ve noticed ... I say myself: 'what's wrong with me? What's wrong?' I was on holidays and I felt great, I'm great!'. But I easily get disappointed at work, with no apparent reason. I still work well with my patients but I am more irascible. Besides I feel guilty, as if I should do more of what I do, as if I must do more. I am usually at my parent's house on Tuesday, Wednesday and Thursday morning, but now I think: 'considering that there might be a day in which… perhaps this*

> *is time to be with her'. I have my own life but I have no children… but I have a partner and I also want to be with him. He is being so patient with me because every time I'm with him, since we got back from holidays, I'm crying, talking about my mother… Then I say myself: 'to what extent ... what should I do? Should I move to my mother's house? Should I limit the time of being with him to take advantage of the present moment with my mother? I really don't know! And my sisters do not help me a lot with this…*
>
> **The Jimenez Family (4)**

For those families who were not able to find a balance care became the centre of family life, at least for some members. The struggled to 'get on with life', outside of caring and they had to give up personal projects, with caring being seen as an 'inescapable' responsibility.

Throughout the study it was evident that each family reacted in its particular way to living with AD and that factors such as previous relationships, motivation to care and the values and beliefs within the family influenced its response and the extent to which 'balance' might be achieved.

The quote below, taken from one of the focus groups, illustrates the complexity of the 'balancing' process. Participants described how *'keeping things together'* was a common aspiration among families living with AD, however at some stage it was difficult for anyone to achieve and caused a wide range of emotions to surface:

> ***Lucas:*** *It is hard because you say: 'why I have to resign to this? Now there is no holiday, always being here… Then you say: 'besides all of this, I have to give up, to stop doing other things…'*
> ***Leonor:*** *I completely agree. It's like you feel furious, you feel furious. Because you're seeing what is happening, and you know what is happening. Then you say yourself: 'well, this is what it is and obviously it is not going to change; besides, it`s getting worse'. You*

> *know the theory perfectly but then, when you are into the situation, you say: 'Oh shit!' This is like if you sometimes get desperate.*
>
> ***Laura:*** *When you think you have the situation under control it becomes out of your control again. That's the problem.*
>
> ***Lisa:*** *Every day is a different day.*
>
> ***Laura:*** *This is a 'day-to-day' and every day is a different day.*
>
> **Leo***: What you have to do is defending your life otherwise... (He raised his voice tone giving emphasis to what he said)*
>
> ***Lucas:*** *yes, yes! I completely agree. You have to take care of your life as well.*
>
> ***Laura:*** *Yeah, this sounds very nice but in real life… Sometimes people said to me: 'your mother has Alzheimer. She got it alright, but you have to keep your life on'. However, this is not just as simple as they see it. It is difficult to keep things together. I mean, you keep living a life that is someway is restricted to… and at times, I still feel guilty. I am not able to enjoy because I'm thinking: 'I have to know how to do this; I will learn how to do that' Then…*
>
> **Leo***: Overuse the kindness of your family and your friends. Overuse it! If you don't do it you will get crazy!*
>
> **FG.2**

While sometimes families were able to care for their loved ones without causing major consequences for the whole, at others times they faced significant barriers in trying to achieve a balance in their newly defined lives

Largely, *'keeping things together'* depended on families being able to agree on how the whole group could adapt to their newly (re)defined family situation. It was clear for many that appropriate outside support would have been much valued but as the data suggested this was often not received and indeed early contact with formal support systems were themselves often conflicted.

Although it was not an explicit focus of the study at the outset it emerged very quickly that families had largely negative experiences with professional services and received minimal, if any support. Indeed sometimes professional contact could be harmful rather than beneficial. This meant that poor relationships were often experienced from the outset and were reinforced throughout. Consequently families usually went through the caring experience alone, this lead to the emergence of the category of *'feeling abandoned',* which were the words that many participants used to refer to how they felt: for most it was a feeling that prevailed thorough out.

6.4 'Feeling Abandoned'

As was clear from the case studies the period surrounding diagnosis was a traumatic one for most of the families. Unfortunately, for some of them the first response from professionals was far from a positive one, with family concerns being written off or ignored; being seen as a consequence of the ageing process itself or other pathologies such as depression. This attitude was found amongst both GP's and more specialist practitioners:

> ***Blanca:*** *As I said before, we went to the doctor and we said to him: 'please, check my mother's health status because it seems that she is not alright'. Well, they completed several screening and assessment tools for AD; these type of tests such as 2+2=4 and so on. However, my mother stated she would not come back to the doctor to do these 'nonsense' things. Therefore the assessment process stopped right there.*
> ***Bea:*** *At the end the GP referred my mother to the neurologist to determine if my mother had something wrong in her head and such.*
> ***Blanca:*** *Yeah, but this happened after having gone there (to the GP's office) repeatedly; over and over again, because otherwise…*
> ***Bea:*** *The neurologist made the appropriate assessments, he referred our case to the memory unit… but the GP… OMG!*
>
> **The Blasco Family (1)**

> ***Jimena:*** *We have been dealing with this issue since 2009. We went to the neurologist and the neurologist said: 'well, there is nothing. It is a matter of ageing'. Well, then great! Fortunately I attended a course*

> *on neuropsychology and met Psychologist A and Psychologist B (popular psychologists in the local area of Navarra); and they made a case in which I saw some characteristics of what was happening to my mother. So once the course finished I explained to Psychologist A what happened to my mother and then she explained me everything. Thanks to her we are here otherwise I do not know what would have happened.*
>
> **Julieta:** *Yes*
>
> **Jimena:** *I do not know what would have happened! And then she gave me an appointment and we started the whole process. She made the appropriate assessments, she also referred my mother to the memory unit, and she confirmed the diagnosis as well. Because otherwise… According to the first neurologist absolutely nothing happened to my mother, just unimportant things related to the ageing process. Well, it's true that neuroimage studies detected absolutely nothing in her. The test did not detect anything; what's more, what we told to the neurologist with regard to the everyday episodes that we lived with my mother seemed to have no relevance to him… By contrast, as soon as Psychologist A saw my mother she quickly realized what happened to her.*
>
> **The Jimenez Family (2)**

These type of responses caused feelings of confusion and uncertainty among relatives since they strongly believed that the person was medically unwell. Some of them, such as the Blasco family, insisted that the GP needed to reassess the health status of their relative. Others resorted to a private medicine in order to get things moving. However the onus here lay with the families and this highlights both the need to be proactive and also the significance of the (expert) knowledge that family holds with regard to what was truly happening to their loved one (*'she was not my mother'*). But this knowledge was often ignored by the professional 'experts' as in the case of the daughter above who felt that the everyday episodes the family provided to the neurologist were seen as irrelevant to the diagnostic process. It seemed to the families that professionals did not care about their accounts and that they overlooked the kind of 'intimate' knowledge that only the family could provide. This was seen to create unnecessary delays in diagnosis. The general dissatisfaction experienced in obtaining a diagnosis that families reported suggested that routine practice often placed too much emphasis on medical insights and not enough on what the family could bring to the diagnostic process.

The focus groups also highlighted difficulties in families' encounters with professional systems. One daughter, Ilda, recounted how there was reluctance to share the diagnosis with the family, possibly due to the stigma associated with it:

> ***Ilda:*** *There are families that quickly notice it (AD) and health care professionals refuse to tell them it for fear. In the medical centre C, I had to tell the professionals: 'please, tell me that she has Alzheimer's disease because I know she has it'. I believe that doctors in general lurched along the process, they move to the right side, to the left side, then to the north and finally to the south... Because we all know that in health care field there are certain words that are terrifying, Al- zhei- mer, can- cer*
>
> **FG.1**

From the data provided in this study it seems that a biomedical approach that placed the emphasis on diagnosis and treatment for the individual still prevails in AD care in Spain. As the various family experiences suggested the focus was largely on individual symptoms and behaviours and any treatment centered on approaches that seek to minimize these through interventions such as medication. Through this lens AD is seen as a progressive condition with little hope for the future, a perspective that could be relayed to the family and even the affected person, as the following daughter illustrates:

> **Ilda:** *Doctors give you the medication, the Ebixa, and that's it. It is understood that there is nothing more to do. I even believed that at the beginning. However, when I went to the C clinic I understood that there were too much to do.*
>
> **FG.1**

For the most part, families reported that they did not receive adequate information and referral to sources of support after receiving the diagnosis. Many reported that professionals did not discuss the next steps or provide information about community-based services. Some families were disappointed that their physician did not suggest a follow up visit to support the family, or only did so after a long period of time. Once again even specialists seemed to have no interest in, or offer to, support the family:

> ***Gemma:*** *It was supposed that, after one month of setting up the treatment, the doctor would reassess my father's state. Well, he started the treatment in June; then July, August, September, October, November, December, January… It took 7 months for the doctor to call us again. Well, we went there and the neurologist, he did not ask us anything. He just cared about if we'd noticed if the disease had progressed.*
> ***Nuria:*** *what about you Gabriel (person with AD)?*
> ***Gemma:*** *Nothing!*
> ***Nuria****: did the doctor ask you something?*
> ***Gabriel:*** *He asked me nothing.*
> ***Gemma:*** *No, no! He did not say anything to him. There was no question at all. He just asked us if we considered the disease had progressed; we said that it did not and that was everything. That was everything. Ultimately the doctor sent to us a letter which said that if the condition progressed he would add more medication. He sent to us a report that said he had already forwarded my dad's case to the memory unit and that in case the disease progressed, he would add more drugs. I mean, I had questions to ask him but apparently he was not, he was not, he was not willing to… (…) That report was…! It just included that in case my father got worse we should add more drugs. When do I know he is getting worse? When? When? If he got worse, if he got worse... The doctor already knew that he was getting worse! But at which point we could say that the condition had progressed? When should have we started adding new things? And what would we get with that? What? What would the improvements be? What? Do professionals know it? Well, I think they don't. I think they don't.*

> *When should have we start with a new treatment? Look, I have the health-report here: 'if this is not going better…' 'What is this?' How are other drugs going to benefit my father? How? I spent the whole summer reading medication leaflets…*
>
> **The Gonzalez Family (1)**

For families what hurt the most was the lack of professional interest in helping them to understand and live with the condition. For many families no effort had been made to explain what was likely to happen hereafter, nor were they given any advice about the impact that the condition might have on their lives. This lack of information about what AD meant for families to led confusion, as exemplified by the following daughters:

> ***Nuria:*** *What do you know about the condition?*
> ***Jimena:*** *Not so much*
> ***Julieta:*** *I just know what I've read and seen.*
> ***Jimena:*** *I refuse to read about, I'm not…*
> ***Julieta:*** *I've read a little about it but… nobody told us 'it is this, this, this, this and that, nobody! You know that she will end up losing her memory, that there are some general guidelines… But we do not really know much about it; thus, there are certain things I consider as illogical ones. I can understand she did not remember where she´d left the bag today morning but, that she has ten sweaters, each one sorted on a hanger… for example, (she re-enacted a past episode she lived) the other day, she had some jackets that I had left in her room. Then I went back the following day and I found all of them mixed with her bags, which were also well organized in the closet. She had thrown them down. There was a shoe here, other one there… I cannot understand this. That, to me, is not related to memory. I cannot understand this. (The daughter gave an example of an episode she lived in which her mother with AD had disorganized the clothes and stuff she had previously organize in her room. She could not understand how these episodes were related to the loss of memory her mother suffered)*
>
> **The Jimenez Family (2)**

This idea was reinforced by Irene, a daughter for whom the condition was completely new. She had no previous contact with it but the doctor assumed that she had some understanding. However, any advice given at that time would have been particularly valuable:

> ***Irene:*** *The first time I went to the see the doctor he did not even look at me. He was all the time with the audio-recorder: 'the daughter says that, the daughter says that...' Then I kept quiet to see if this way he looked at me. Not to mention the times I went there with my mother. He checked her really quickly; he did not pay attention to her so I felt very uncomfortable. He did not stop to explain to me what she had, He just said to me 'she has a cognitive problem, a cognitive problem…' 'But what did it imply?' Because I noticed my mother was doing weird things… because beside the loss of memory there were other things. And it was supposed I had to know what meant having a cognitive problem of this kind…*

FG.1

In the same vein, any understanding that David had of the condition came from informal sources such as the wife of a friend, who had lived with a relative with AD. He therefore managed certain aspects of the condition based on the advice that she had provided to him:

> ***David:*** *Nowadays you see many people about my age that are living the same problem (caring for someone with AD). I have a friend whose wife has her mother in a more advanced stage. So she helps me a lot. And we talk about things. Especially, when my mother started telling me weird things, she told me I should have in mind that they behave like that because they have a problem in their brain and they do not have bad intentions... these kinds of things.*
>
> ***Nuria:*** *David, have you received any other information from professionals or…?*
>
> ***David:*** *No. Nothing, nothing in particular.*

The Dominguez Family (2)

The data suggested that families were ‘left to get on with it’ once they received the diagnosis. The reality was that families needed compassionate help to understand and respond to the full implications of the condition. They needed professionals to listen to their fears and concerns, provide information and to assess how they all were managing to adjust to their new situation. Families experienced a huge range of emotions following diagnosis and needed these to be acknowledged and addressed.

Unfortunately families were left largely to their own devices, and some, such as the daughter below had to take things into their own hands and undertake some organised training:

> ***Marta:*** *the first thing I did when my mother was diagnosed with it, was to deny it. I just cried, I had a few anxiety attacks... the first time I came here (to the association), the psychologist B supported me so kindly! Then I decided to start studying the condition; I have been studying this issue for about two years and I am currently working with dependent people.*
>
> ***Magdalena:*** *My case was the contrary, the contrary. I did not want to know anything about this. I mean, I’ve came here and yet I do not know why.*
>
> ***Marta:*** *I understood that I had to care for my mother the best way possible; I wanted my mother to have an acceptable quality of life and I would do whatever was necessary to care for her. I mean, my life, this is as you've you mentioned before; I have organized my life based on what my mother needs, what she needs. She is the first priority of the day, as I said before. Therefore I plan my life base on that. Does your life change? You can imagine to what extent... but you can do it. I started to study because I said myself: ‘Well Alzheimer's disease, I know this implies memory loss... so what? How may I cope with it? What situations may occur and how may I face them?’ Therefore I decided to start learning about it. Finally I got two certificates; this took me lot of time, lot of, lot of time and effort. Until I accepted what happened to my mother I suffered a lot. It was terrible, it was terrible. I did not want to accept it and I denied it; I said: ‘no,*

> *this is not happening'. At that time I felt I needed some guidelines, some resources to accept it, so I decided to learn about it. And I admit it was a good thing. In fact I'm currently a family support worker and I work with families of dependent people. I've been about four year years working with them*
>
> **Magdalena:** *So you've seen something positive to this.*
>
> **Marta:** *Of course!! I think I turned it over. I understood I had to help my mother; I wanted her quality of live would be as good as possible so I began to study. I did not know if I´d be able to do it or not... But I handled it better than I expected. Now my mother does not make me feel stressed as my sister does. Not at all! I live quite normal my mother's situation. My stress comes from the other side (family conflict), Much more!*
>
> **FG.3**

This case however was the exception rather than the rule and most families really did *'feel abandoned'.* They reported a lack of information about the resources that were available and how they could access. Families described going blindly through the health care system, stumbling from one place to another without any guidance or clear idea of the steps they should follow. The lack of guidance and support increased stress in families, especially for those that lacked personal resources and were family dynamics were already poor.

As described above in such circumstances families relied on peers, people who had already lived with similar situations and had prior experience, such as friends, relatives and neighbours. Therefore most of the families' decisions and actions were based on 'popular knowledge'. However this was often piece-meal and arbitrary, with little coordination:

> **Gemma:** *This is a non-stop. This is too much. I really need someone that tell me things, someone who I can ask for things about my dad. I do not know! This is too complicated because some issues need the competence of the social worker, then I heard others ones are processed through the memory unit. I've also heard there is a district-*

> *unit... But I’m getting to know these things because people in the street tell me about them. (...) Because I do not know what kind of resources I have. I do not know if there is... these are like stuff you are finding out as you go along. However, I do not have a comprehensive scheme of what resources exist and which one we can access to. I do not have that. For example, a cousin of mine works as a volunteer in a home-care program. Then I ask myself: what is that about? How does it work? For whom is this aimed? I know there are some resources but I do not know at whom they are aimed. Do they consider the economic status, the level of dependency of my father had… I mean, I do not know if they take into account the level of impairment, the family income... I do not know! Other friends told me about the Red Cross services. There is a volunteer service that for example helps family in bathing task, if the person required practical assistance for that. So there are people who voluntary help but I did not know about that. Then I stumble around and that makes me feel insecure*
>
> **The Gonzales Family (1)**

> **Elisa:** *We were really lost at the beginning. We said: ‘OMG, how awful is this!’ You have to trust the professional (...) There is not an established treatment, an established protocol. There is a need for guidance but ultimately it is the family who have to organize things.*
>
> **The Estevez Family (3)**

The two daughters below make explicit the total absence of specific interventions tailored to the stage of the condition and the care-giving history. Although AD may differ greatly from one person to other and its impact on families is not homogeneous, some general stages can be identified as well as key transitional points in the care giving process. These may help to inform the support families require at any point in time. Some resources may be helpful for some families and not for others. The stage of the disease and the family history may not only serve as a guide for clinical treatment but also to establish and develop professional resources according to the needs and circumstances of the family and the way that they perceive the needs of their relative in order to maintain their dignity:

> ***Gemma:*** *I think that what everyone forgets is that, even some professionals do it, this condition develops in stages. Then the time I went to visit the social worker and she just told me that there were some activities in some day care centres I got.... 'Look, my father is not going to a day care centre'. My father is not, he is not as bad as…. If my father were there he would feel alone. He is not... I think he would feel worse than he feels now. This would hurt him and his self esteem, because I think he still has certain capacities that... no, no. Yet it's not the time for... I think the professionals do not know how to guide us. Because they need to know in what stage is he? In what stage is he? If he is in this one he will need some things; and if he is in the other one he will need other things. Professionals do not know!*
>
> **The Gonzalez Family (2)**
>
> ***Carla:*** *The nurse and the GP gently asked me why my mother did not go to a day care centre. Then I told them that I did not agree with them. I said to them that my mother would not attend to a day care centre for now. She is still very active. I will not have her sitting on a chair. You know what I mean? She still goes to the social club, she sews, she draws, and she makes some writings… I mean, she is, she has her cognitive function very active. I am not leaving her as... And I think that all these things that my mother keeps doing benefits her a lot. Because I notice that other people, my mother in law for instance, she is alone and she does nothing. She is much impaired than my mother is.*
>
> **The Cervera Family (4)**

The lack of support directed to the whole family and especially toward helping them to redefine roles and responsibilities, to discuss things in order to prevent or resolve disagreements around care, meant that families really did feel totally alone. When families were asked about what could have helped them at a given point they often said that rather than disease specific or practical advice they would have preferred help with negotiating care within the family:

> ***Gemma:*** *Look, the truth is that if we would like some psychological attention or something like that. That they (professionals) call us, as a family, and they organize your family, yeah, something like that, you understand me? That someone, instead of me, tells my sister that… Someone that help us; if this were possible… it would be wonderful. Someone that contact with us, that someone call us rather than we have to call them; Let's say the social worker, someone who may ask you how you are or how you are not, that tells you that this stuff may happen in families. I mean it feels like we all are sick; actually it is not just my father who is sick; it is that we all are. We feel overwhelmed and everyone experiences this in a different way. Each one has their own needs. I see myself deprived of freedom; my sister does too but in a different way. (…) Yes, but if someone could advise us: 'look you are going to find this kind of troubles. Then, what most people usually do is that one takes control of medication, the other one cares about this, the other…' We need to organize! Then if someone from outside explains this to us...*
>
> **The Gonzalez Family (2)**

As the quote below suggests some thought that I could provide information:

> *Jimena: I was coming here with the idea of asking you where can we go to have more information about the disease and certain help to us because besides we have no information, we do not know how to manage our conflicts…then, there are a lot of things, then I think we need professional help*
>
> **The Jimenez Family (4)**

The experiences that focus group participants shared regarding professional care during the early stages of the condition closely mirrored those of the families interviewed. However, they went a little further suggesting that they not only felt abandoned at the beginning of their experience but throughout the whole caring process to date:

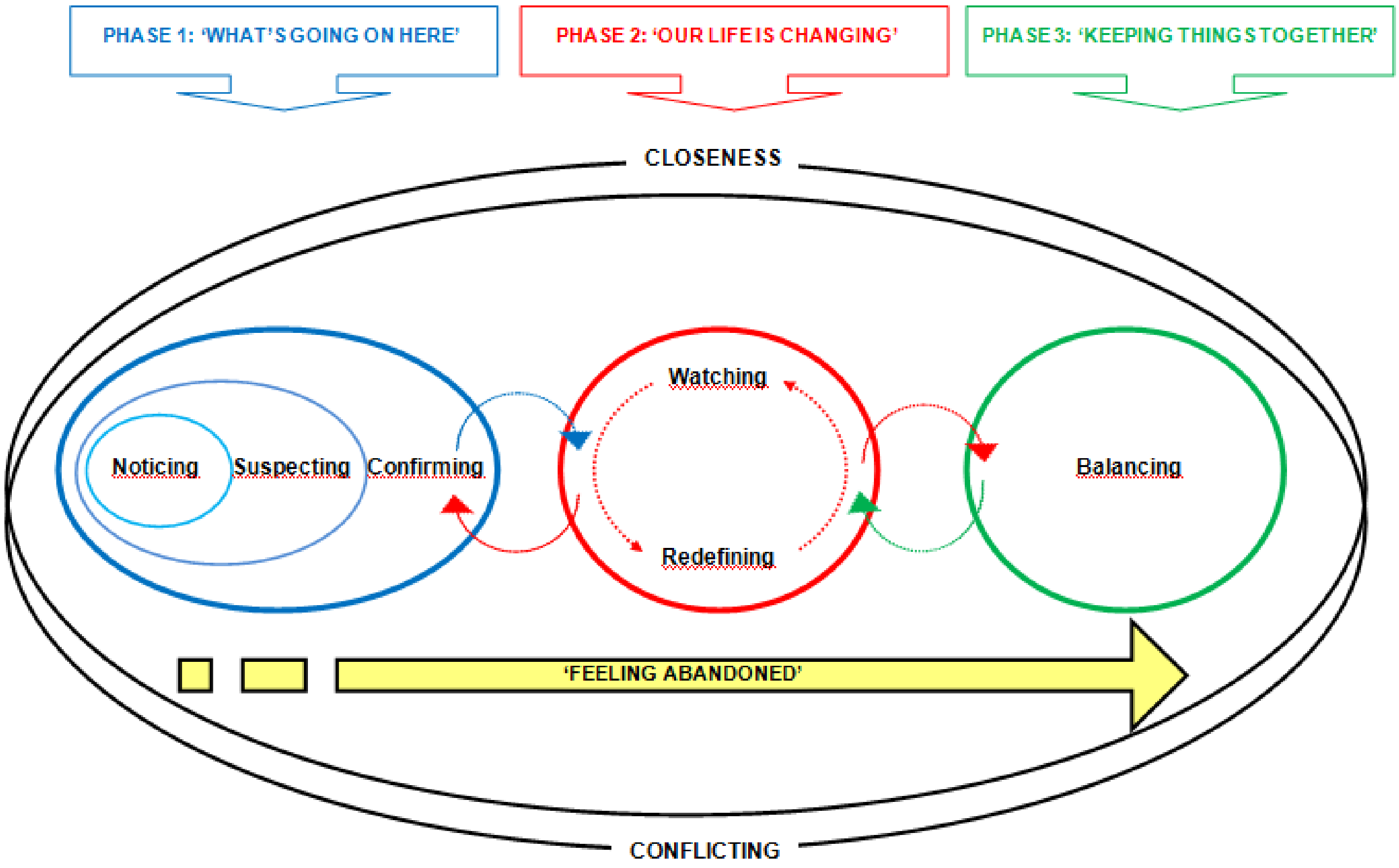
> **Nuria:** *Do you 'feel abandoned'?*
>
> **Laura:** *You have to get by*
>
> **Lucas:** *They leave you in God's hand*
>
> **Lisa:** *We are alone at the beginning, at the end and in the middle.*
>
> **Nuria:** *Do you think you needed some support at the beginning?*
>
> **Leo:** *Someone to guide us. We needed guidance. We were completely lost: 'What is coming over me, my God!' We needed a support, a reference.*
>
> **Laura** *In the public health care system there is nothing. Where can you go? What you can do? If the GP even does not know…*
>
> **FG.2**

Summary

The three-stage model of the subjective experience of families living with early stage AD presented had made account of the dynamic and temporal dimension of the AD experience. References to the family case studies as well as the typology of family dynamics has been used to explore the key social process of 'noticing', 'watching', 'redefining' and 'balancing' which underpinned each stage of the whole model, named 1. *'what's going on here'*, 2. *'our life is changing'* and 3.*'Keeping things together* (Figure 6.1 below provides a visual representation of the model and the family dynamics). The last part of the chapter has addressed an overriding theme that emerged across all three stages, the families perception of *'feeling abandoned'*, which captures the experiences that families had in their contact (or more often no contact) with the professional support provided at each stage of the AD process. The importance of countering the perception of *'feeling abandoned'* by providing more adequate and stage-tailored support services will be considered in the discussion chapter.

Together with the typology of family dynamics presented in Chapter 5 they highlight the major findings to emerge from this constructivist grounded theory study. Before going on to consider the implications of these, attention is turned to the quality of the study.

Figure 6.1Three-stage model of the subjective experience of families living with early AD



CHAPTER 7

EVALUATION OF THE QUALITY OF THE STUDY

In the Spanish context this study was novel in its design and its desire to explore the experience of the 'whole' family, including not only the caring dyad but also to include other family members and their relationships when living with Alzheimer's disease (AD). This approach led to an in-depth understanding of the lived experience of older people with AD and their relatives, within their family context. It is hoped that the study makes an original and significant contribution to knowledge through the identification of a typology of family dynamics, presented in chapter 5, and the development of a three-stage model of the subjective experience of families living with early stage AD, presented in chapter 6. Furthermore, the findings of the study offer insights to promote the development of innovative family support services tailored to early stage of AD and directed not only to the person with AD and the caregivers but to the whole family unit. These issues will be explored in the next chapter.

Prior to discussing the finding of the study, this chapter offers a brief discussion about the quality of the grounded theory (GT) produced by applying the criteria for GT studies suggested by Charmaz (2006) (i.e. credibility, originality, resonance, and usefulness). The extent to which the study might be said to have met these criteria is considered below.

7.1 Evaluation of GT

As discussed in Chapter 4 a constructivist GT approach was adopted in this study following Charmaz's version of the methodology (2006). Thus it is logical that the evaluative criteria that she developed to assess GT are applied. These are *credibility*, *originality*, *resonance*, and *usefulness,* and I will now consider the resulting GT in relation to each of these using the questions that Charmaz suggests. Ultimately, however, it is for the reader to decide if these criteria have been met but below I present my views.

Credibility

Charmaz (2006, p.182) suggests the following set of questions as a guide to evaluate the credibility of a GT study:

- *Has your research achieved intimate familiarity with the setting or topic?*

As I described in early chapters of the thesis I conducted a broad review of the literature, which together with my own experiences, were used to identify the sensitising concepts and foreshadow questions that guided the study. The purpose of this was not to impose predetermined ideas and existing frameworks onto the research but rather to develop a critical understanding of central concepts related to the study and to identify potential leads that might guide the initial direction of the study. As Urquhart (2007) suggested *'there is no reason why a researcher cannot be self-aware and be able to appreciate other theories without imposing them on the data'* (p. 351).

Moreover as also explained in the introductory chapter I already had some familiarity with the topic of dementia family care, both personally and professionally. All of this provided me with some initial experience with the topic.

Subsequently fieldwork and engagement with family participants extended over a period of time and a number of visits. This allowed me to establish rapport and trusting relationships with participants in order to share their experiences of living with AD and to gather rich and in-depth data. In addition, the development of data collection over a series of interviews with each family allowed me to gain a comprehensive understanding of the family unit, its dynamics and its particular experiences of AD, as well as, to confirm data through the accounts of the different members that took active part in the study. On this basis I believe that this criterion has been met.

- *Are the data sufficient to merit your claims?*

As noted, I gathered extensive volumes of data from various members of the family, in both individual and group interviews over a prolonged period of time. Following the principles of GT I adopted a variety of strategies to analyse the data. I have used large amount of data to illustrate the family case studies presented and to support the identification of a typology of family dynamics in living with AD. I have also presented a three-stage model and the processes that underpin each stage. These are again supported with extensive quotes that family participants provided during the interviews.

Once the potential model was developed I presented it to participating families as well as other family caregivers in the focus groups. These accounts confirmed and expanded the stages and processes comprising the model. These strategies allowed me to combine the research participant's experiences with my own and I consider that in combination the data are adequate to merit the interpretations, statements and conclusions that have been made.

- *Have you made systematic comparisons between observations and between categories?*

This was achieved through the use of the constant comparative analysis method suggested by Charmaz (2006). Each piece of data was examined and compared with each other piece of related data, and the concepts or ideas emerging from the data and categories developed were compared with each other.

I analysed the interview transcripts as soon as possible after each round of interviews, this facilitated the process of theoretical sampling. I also wrote case-based memos after each interview that allowed me to capture initial ideas and make comparisons between participants' accounts, both across the successive interviews with the same family and between different families. These memos also assisted me in reflecting both methodologically and conceptually, which enriched data analysis and enhanced further data collection.

Comparisons were also made between new data and theoretical ideas already created. As data analysis progressed, patterns and relationships within and between categories, and preliminary theoretical explanations were further explored and refined through constant comparison.

- *Do the categories cover a wide range of empirical observations?*

To achieve this I used theoretical sampling of families and topics. I interviewed families on several occasions and different members to ensure that I covered a wide range of empirical incidents. Examples of these strategies have been provided in preceding chapters and it is believed that given the implicit boundaries of research projects of this nature (as a part of Ph.D. studies) I have met this criterion.

- *Are there strong logical links between the gathered data and your argument and analysis?*

The use of the constant comparative method ensured that the emerging theoretical model was closely and logically linked to the data. Moreover, data collection, data analysis and sampling were interrelated and occurred simultaneously among family participants who were closely involved in the study and consequently brought meaning to the findings. This helped to ensure the integrity, credibility and trustworthiness of the final theoretical model which was co-constructed by participants and me, ensuring that it fully reflected the participants' experiences and meanings.

One of the most important pillars of quality GT research is the reflexivity showed by the researcher throughout the entire process. Jootun et al. (2009) state that *'reflecting on the process of one's research and trying to understand how one's own values and views may influence findings, adds credibility to the research and should be part of any method of qualitative enquiry' (p.42).* Reflexivity refers to being consciously aware of the knowledge the researcher has and how it was acquired and the extent to which this knowledge potentially influenced the results of a particular study. Clearly, reflexivity is a process of constant questioning in which the researcher is recognized as exerting an influence on the study findings. In this sense, GT methods require a strong reflexive attitude by the researcher since all of the phases are closely related and highly dependent.

I tried to capture this principle by recording reflections in a research diary of what influenced my interpretation of the data and my relationship to the research topic and the participants. I also used my reflections on data collection and analysis and interpretations and insights to shape emerging conceptual ideas. In addition regular meetings and discussions with supervisors, both face to face and via email, also encouraged me to question my assumptions. These meetings provided an opportunity to redress potential imbalances, soliciting a range of different views from other individuals. Finally I was open to a reinterpretation of ideas and the need to re-gather data in areas that challenged my initial assumptions and pre-conceptions. Thus I immersed myself in the data and tried to understand what the participants saw as being significant and important to their experience. In this study fieldwork notes and memos provided an ‘audit trail’ for other external readers.

Member checking was another strategy undertaken in the current study in order to ensure strong logical links between the data, analysis and interpretations. The way I implemented this strategy is addressed below.

Member checking

Following the foundational assumption of constructivist inquiry that all the stakeholders should be part of the process of knowledge production (Nolan et al., 2003), engagement of participants in the interpretation and analysis of the data was particularly important. Thus in this study there was a typology of participant involvement.

For instance, as a part of the co-construction of knowledge, participants were constantly involved in data analysis to ensure that the findings represented a shared creation (Charmaz, 2000). For that purpose I asked participants for feedback on major findings. This constituted a good opportunity to receive useful and interesting contributions which elaborated upon the findings. ‘Co-construction’ did not only involve participants in data analysis but also formed part of the member checking process in which data, analytic categories and interpretations were probed with participants to explore the findings and the emerging theory and ensure that a good quality GT was produced (Lincoln and Guba, 1985).

Considering that the credibility of a GT study is concerned with the extent to which the association between the data and the research conclusions are strong and logical, and the extent to which the researcher accurately interprets the collected data as viewed by participants (Charmaz, 2006), I encouraged an active negotiation between myself and the participants so that the emerging theoretical model was based on shared efforts. Participants' feedback suggested that the processes and factors described in the model made sense to them and could be recognized as part of their daily reality.

Member checking was conducted throughout the study by using strategies such as:

- Rephrasing what participants said during the interview and reflecting and checking my interpretations back to them, and asking what they meant by that idea.
- Addressing issues which were raised by families during earlier interviews and considered important into subsequent encounters.
- Providing a summary of the key points that were discussed at the end of the encounter, and thus confirming my understanding with participants,

Hence continuous member checking was developed in which I took data and their interpretation back to the family participants to ensure their accuracy and enhance the credibility of the study (Rodwell, 1998).

The overall research findings were also shared with participants for their comments and feedback. For this purpose I arranged a final encounter with the families to present the major finding across the data as well as a particular case-study from their own experiences. To do so I draw up a time schedule of the main family processes identified and illustrated by some interview quotes. This allowed me to present key findings to participants through concrete and particular examples. Then families commented on the scheme and provided interesting inputs that both corroborated the findings and nourished the development of the final theory. In concluding the encounters families were asked if they felt they were able to identify with the schedule and interpretations presented, to which all responded affirmatively and agreed on how their experiences were captured. The following participant's words offer an example of this:

> ***Bea:*** *Yeah, we see ourselves here*
>
> ***Blanca:*** *Yeah, totally!*
>
> ***Bea:*** *And hopefully this may serve to do something because there is great need to do it*
>
> **The Blasco Family (5)**

> ***Gemma:*** *You've reflected it very well, yeah*
>
> ***Nuria:*** *I'm glad to know you recognize your family experience in here*
>
> ***Gemma:*** *Yes, I am quite surprised about it because it is not easy, but yes of course.*
>
> **The Gonzalez Family (3)**

Co-construction of the findings was also carried out with other family caregivers of people with AD. To do this three focus groups were conducted with relatives of people with mid-advanced stage of AD that attended the regional association (AFAN). They were selected as it was thought that, being relatives whose loved one was in a mid-advanced stage of the disease, their experiences could provide new insights into the study findings while also ascertaining if the processes identified made sense to them.

An oral presentation of the study, including the emerging theoretical model and its stages, was given at each of the focus groups. Key family processes were explained in a temporal fashion and supported by examples elicited from the family interviews. This assisted participants to think about their relevance to their own situation. During the presentation some questions about key process were posted to encourage group discussion.

As with the study families, participants in the focus groups were asked if the processes described and the general model presented corresponded with their own experience, to which they responded affirmatively. In this sense the focus groups served to not only confirm but to refine the processes and model that was developed

- *Has your research provided enough evidence for your claims to allow the reader to form an independent assessment –and agree with your claims?*

In order to give enough evidence for the readers to judge and form an independent conclusion about the credibility of the interpretations, a comprehensive and detailed explanation of the research process, the study findings and its implications have been included.

Research findings have been presented in detail in two chapters. Substantial description has been provided in the family case studies, presented in chapter 5 of the thesis, and a visual representation of the typology of family dynamics has been also offered. Similarly the theoretical model emerged has been presented following a temporal sequence. The processes that underpinned each stage of the model, were supported by verbatim quotations from participants.

Much of the information about the methods (sampling, data collection, data analysis) that were implemented throughout the study have been described in the methodology chapter in an attempt to add further transparency to the research process. On this basis it is contended that sufficient detail has been proved to enable a reader to form an independent assessment that hopefully agrees with the claims made.

Originality

The quality of this GT study also depends upon developing a range of relevant and creative conceptual categories that offer new understandings in the area of study. In this regard Charmaz suggests that researchers should ask the follow questions (2006, p. 182):

- *Are your categories fresh? Do they offer new insights?*

In terms of the originality, the study was novel since there was little prior knowledge about the experience of the whole family unit of living with AD at the time the study commenced, especially in a Spanish context.

Many of the categories produced and the insights offered are, as will be explored in the next chapter, resonant with prior models of the dementia experience but these have been extended and applied to differing contexts, not only culturally but in terms of the unit of study (i.e. the family). The three-stage model and the processes that shaped it offer original insights that should help to promote more sensitive and appropriate forms of professionals support for the family from the beginning of the AD experience.

- *Does your analysis provide a new conceptual rendering of the data?*

The findings, to the best of my knowledge, have not yet been identified and described previously in either the cultural context or the unit explored, and so the analysis can be said to provide a new conceptual rendering of the rich data. As will be discussed in the next chapter some of the concepts and processes that emerged resonate very closely with other author's work in dementia care field, such as the process of 'watching' and notions of, anticipatory, protective and preservative care (Bowers, 1987); or the '*noticing'* process previously developed by Keady (1999). However the current study offers a substantially different interpretation of these and develops them in a differing cultural context.

- *What is the social and theoretical significance of this work?*

This will be discussed in the next chapter.

- *How does your GT challenge, extend, or refine current ideas, concepts, and practices?*

This will also be considered in the next chapter.

Resonance

The specific criterion addressing the resonance of a GT study includes the following questions (Charmaz, 2006, p. 182):

- *Do the categories portray the fullness of the studied experience?*

Resonance was achieved by ensuring data saturation through theoretical sampling (Glaser and Strauss, 1967) and by verifying the completeness of the findings and the emerging model through member checking with the family participants as well as with other family caregivers. Both family and focus group participants suggested that the model comprehensively captured the stages they lived through with early stage AD and fully portrayed their family caregiving experiences.

Resonance has been further strengthened through providing sufficient data and presenting family case studies with extensive background information about the family participants.

- *Have you revealed both liminal and unstable taken-for-granted meanings?*

Participants' feedback suggested that the study findings helped discover a number of barely perceptible and taken-for-granted meanings of their experiences, particularly the theoretical model and the processes it identified. This helped family members to think about their experiences differently and have a better understanding of their situation. The findings also challenged and expanded my own assumptions and it is hoped that they will do the same for readers of this thesis.

- *Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?*

Family's accounts raised diverse issues regarding the health and social care they received (or largely, had not received) and the impact this had on their experiences. Thus numerous health and social care implications emerged from the study and these will be further explored in the next chapter.

- *Does your GT make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?*

Since this study is a co-construction between participants and the researcher, the final theory should make sense to participants as it emerged from their experiences. This was achieved through participant feedback and verification of the final theoretical model. These procedures were conducted with family participants, as well as with a group of relatives who had gone through the experience. This indicated that the model and its stages made sense to them and that they could recognize its relevance to their daily lives. This was further enhanced by using ideas and language that was accessible to participants and drew, wherever possible, on their own words.

Usefulness

Usefulness refers to the feasibility and workability of the theory, and examines the following issues (Charmaz, 2006, p. 183):

- *Does your analysis offer interpretations that people can use in their everyday worlds?*

The results of the study and the emerging theory were confirmed as useful by the study families and the other caregivers during member checking. They commented that they could see themselves and their families moving through each stage of the model, and thought that the findings captured what they had experienced when living with the early stages of AD. They were also able to recognise the specific processes and care strategies from their own daily experiences. Family caregivers also suggested that the findings offered useful information and could be used to develop support services tailored to early stages, since all agreed that there was no support at this stage and that *'feeling abandoned'* was a shared experience. This will be explored further in the next chapter.

- *Do your analytic categories suggest any generic processes?*

The generic processes of 'noticing', 'watching,' 'redefining', and 'balancing' were identified and their dimensions have been fully explored.

- *If so, have you examined these generic processes for tacit implications?*

This will be considered in the next chapter.

- *Can the analysis spark further research in other substantive areas?*

This will also be explored in the next chapter.

- *How does your work contribute to knowledge? How does it contribute to making a better world?*

This is another consideration for the next chapter.

Based on the arguments offered above I consider that this study can be said to have met the criteria described by Charmaz (2006).

CHAPTER 8

DISCUSSION AND CONCLUSIONS

Introduction

The main findings and the resultant three stage model of the subjective experience of families living with early stage Alzheimer Disease (AD) were described in Chapter 5 and Chapter 6. The family case studies gave an account of the circumstances and context of the family units to provide a background for better understanding the temporal model of the subjective experience of AD. This was developed by exploring the impact of AD on family dynamics which played such a key role in shaping how the family responded to AD.

Within this chapter I will reflect on the above in the light of the existing literature. Additionally an exploration of a number of important ideas within health care literature will be provided, including, the emergent advocacy of a family system approach in dementia care field and its relevance to families living with this condition. This includes the need for professional support interventions targeted at the varying stages of the family care journey.

The implications of the study for education, practice, policy and future research will be considered.

8.1 Contribution to Knowledge

As was acknowledged in Chapter 3 there has been an extended history of research that has explored the experience of caring in, and to a lesser extent, living with dementia, mostly focussed on AD. However the majority of studies have focussed primarily on the carer’s perspective or that of the person living with the condition. More recently studies have taken a dyadic perspective, exploring the experiences of both parties (see for example, Hellström et al., 2005, 2007).

However it was a fundamental assumption of this study that such designs cannot capture and represent accurately the experience of the family as a whole. The present study was therefore novel, at least in a Spanish context, in adopting a family systems approach, considering the person with AD as part of the family unit and not as a separate. The study not only focused on dyadic relationships (person with AD – main caregiver) but included other members, consequently providing a more in-depth understanding of the lived experience of the whole.

The family system approach adopted in this study has permit a more comprehensive understanding of the interaction of family and AD over time and the impact this can have on the family dynamics and working style to emerge. The study findings have provided insights into a typology of family dynamics and the factors that may influence the way these develop. As will be highlighted later this can assist professionals to better understand the family experience of living with early AD and plan appropriate support services. Additionally the temporal three stage model developed from the study findings provides valuable knowledge about the key processes that take places in the family during the early stages of the AD experience. This again has implications for the support needs of the family at various points in time.

I will now consider in greater detail the extent to which the typology of family dynamics developed and the three stage model that emerged is consistent with but also extend existing theoretical models both in dementia and more widely in the field of family care. Given that modifiability is considered a key feature of a good GT (Charmaz, 2006) I believe that by comparing the substantive mid-range theory developed in this study with other works this will help to demonstrate both points of agreement and of elaboration providing the opportunity of developing a formal mid-range theory.

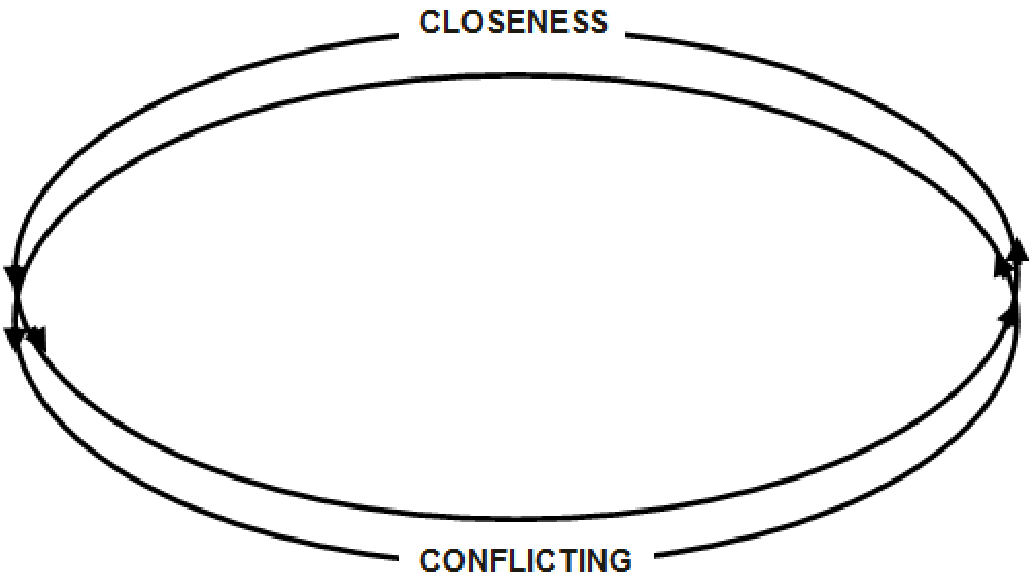
8.1.1 The Impact of AD on Family Dynamics

Even though the experience of each of the families participating in the study was in some way unique a comparison of their different cases identified a range of dynamics that shared certain characteristics. These are summarised below:

- **Close dynamics at the start and throughout the experience**.
- **Close dynamics at the start which became conflicting.**
- **Conflicting dynamics at the start and throughout the experience.**
- **Conflicting dynamics at the start which became closer**.

These capture the different ways in which family dynamics might change following the onset of AD. Broadly speaking it seemed that families whose existing relationships were characterised by affection and commitment were more likely to remain close despite the everyday challenges they encountered in living with AD. This helped them to find meaning in their caring activities and to see the positive dimensions. Conversely families that perceived caregiving as an obligation and had poor prior relationships were more likely to find difficulties in reaching agreement and their relationships were likely to remain conflicting. In these two scenarios AD mirrored existing patterns of working and being in families.

However in other cases the opposite could happen and the presence of AD and the resultant caring situation altered the dynamics of some families for the better or the worse. Families who were close could become conflicted and those who were conflicted might move closer together as they worked to address the challenges the condition posed.



The typology developed has suggested that the nature and quality of preceding and present family relationship and interactions are significant factors influencing the experience of AD for all members. Correspondingly it has provided insights into the impact that this condition and the resulting caring circumstances have on the original dynamics of the group. Therefore these findings reinforce the value of research and practice focusing upon family dynamics, and suggest the importance of an adequate assessment of family-relationship and interaction history if more comprehensive and individualised support strategies want to be achieved in AD care.

The relatively recent growth of interest in a relationship-centre approach to dementia care (Nolan et al., 2004; Nolan et al., 2008) has involved placing people with dementia and their caregivers at the centre of research and policy strategies development, an approach that is being more widely adopted (Quinn et al., 2009; Quinn et al., 2012; La Fontaine and Oyebode, 2014).

The changing nature of family interactions and dynamics during the course of AD identified in this study is broadly consistent with the findings of preceding works (for example that of Keady and Nolan, 2003; Hellström et al., 2005, 2007) that highlighted the significant role that relationships play in the caregiving experience in dementia. Nevertheless, the majority of these studies took a dyadic perspective predominantly considering marital relationships. Attention has rarely extended to other types of family relationships and the potential impact that the condition may have on the whole family system.

The few studies that have explored the wider family experience indicate that dementia affects other members of the family and not merely those included in the dyad person-caregiver (Algado et al., 1997; De la Cuesta and Sandelosky, 2005; Peisah, 2006). These studies argue that the condition impacts on the family unit as a whole, as was evident in the current study. AD and the resultant caring situation impacted on the dynamic of the group affecting for instance relationships among siblings and between children and parents, for the better or the worse, and thus altering interactions across the whole family system. The findings of this study therefore support the importance of considering other types of relationships, rather than the dyad. The inclusion of the wider family is therefore crucial if we are to obtain a more complete understanding of the family experience of living with AD.

The types of dynamics described in this study have significant parallels with the work on the dynamics of dementia elaborated by Keady (1999) and Keady and Nolan (2003) and the findings of recent systematic reviews of quantitative (Quinn et al., 2009) and qualitative studies (La Fontaine and Oyebode, 2014). Such authors argue that the type and quality of previous relationships, or what Keady (1999) coined as 'building on the past', play a central role in shaping the ways in which family dynamics are influenced by AD.

As with prior work on dyadic relationships the present study supported the assertion that the nature of prior family dynamics and the ways in which they were able to negotiate and agree (or not) how family roles and relationships had to be 'redefined' in response to AD. This often required a considerable degree of effort on the part of some or all of the family and it is suggested here that this is consistent with the notion of 'working' as argued by Keady (1999; Keady and Nolan, 2003).

Keady argued that various types of working patterns could emerge depending on the extent to which the person with dementia and family carers were open with each other. Four main types of 'working' were identified and these were:

- 'Working together' – describes the 'best' case scenario when there is shared and early recognition of the symptoms and help is sought jointly. Fears and concerns are recognised by the GP, and appropriate specialist advice is taken.

- 'Working alone' – occurs even when there is no shared and early recognition of the difficulties that the person with dementia has, as he/she is likely to have kept their initial concerns secret for some time and will have been 'working alone' to hide them. Furthermore, both carers and the person with dementia are often left to feel that they 'work alone' when their efforts to seek professional help do not get the appropriate response.

- ‘Working separately’ – describes the instances where the person with dementia is working alone to ‘keep things hidden’, and the carer is also actively ‘increasing vigilance’ so that a situation occurs where both parties are investing considerable effort but are ‘working separately’, each trying to make sense of and respond to their circumstances. When the person with dementia is very adept at ‘keeping it hidden’ and carers accept this behaviour as normal, then this period of ‘working separately’ can be prolonged.

- ‘Working apart’ – usually occurred when prior relationships between the carer and the person with dementia had not been good, or when difficulties in the ‘working separately’ period lead to strained interactions. Consequently the carer and the person can ‘work apart’ so that their relationship deteriorates and the carer feels increasingly trapped in their role’ (Keady and Nolan, 2003, p. 29-30)

As the descriptions above suggest these patterns were largely shaped by the degree of open communication and agreement that existed between the parties involved. The typology of dynamics presented in this study has distinct similarities as does the suggestion of *‘keeping things hidden’* (‘hiding’ in this study). It is easy to see how families who had initially close relationships that remained so were ‘working together’, as were those whose relationships were initially more distant but became close. Conversely, some families had always tend to work apart (those whose relationships had always been and remained conflicted or became so in response to AD). In cases were AD had caused family rupture some members chose to work alone and apart from other family members.

It is also suggested here that processes such as ‘noticing’, ‘watching’, ‘redefining’ and ‘balancing’ should also be seen as other important forms of ‘work’ that the family engage in when living with AD. These will be considered in more detail later

More recently La Fontaine and Oyebode (2014), in their synthesis of qualitative studies, acknowledge the centrality of the family relationship history (‘a shared history’ as they refer to) as one of the major factors affecting the quality of the caregiving experience. Their ‘good life together’ category mirrors the existing close family dynamics identified in some families in this study. Here, just as in this study, a good existing life together and strong emotional bonds had motivated family members to support each other prior to AD and enabled them to maintain positive interactions when living with AD. As La Fontaine and Oyebode (2014) note, the positive relationship history helped people to resolve or accommodate potential disagreements. On the other hand the idea of ‘disconnectedness’ developed by La Fontaine and Oyebode (2014) describes the prior conflicting dynamic of families in this study. Here a poor shared history, an apparent absence of emotional connectedness, and long-standing conflict and disagreement led to negative outcomes in caregiving, and made more difficult for people to work toward connection and commitment in relationship.

Based on their synthesis of studies the same authors developed the idea of negotiating the impact of dementia upon relationships (La Fontaine and Oyebode, 2014). This reflects the dominant family work style and the impact it has on caregiving. These authors argue that dementia may be regarded as a challenge to be managed together, consistent with the sustained commitment to family and care that families with closeness dynamic demonstrated in this study. On the other hand the authors distinguish this from the ‘working apart’ experience, described by Keady and Nolan (2003). Again this is consistent with the arguments made by me above. In such circumstances this leads to a feeling of *entrapment in the family care-giver’* (La Fontaine and Oyebode, 2014, p.1259) as described by a number of participants in my study.

8.1.2 The Temporal Dimension of the AD Family Experience

In addition to the above I believe that the current study both builds, and extends, current understanding of living with dementia as a temporal experience especially in the early stages through the development of the co-constructed three stage model of the subjective experience of families living with early stage AD. The model and the stages it comprised give an elaborate account on how families who are confronted with a new and challenging dimension of family life respond to the demands they face. Consideration is now given to this three stage model, particularly the process that shape it, and the parallels that exist with other (earlier) works on dementia and family care.

‘Noticing’

It is in the first stage of the model, *‘what’s going on here’*, and particularly the initial process of ‘noticing’, that the closest parallels to existing work can be found, particularly the work of Keady (1999) exploring the dynamics of dementia. My familiarity with the literature prior to starting the study meant that I was already aware of this idea and when families in my study started to use the word ‘notice’ themselves I deliberately followed this up.

As with Keady’s work ‘noticing’ describes the process by which the family, including the person with AD, become aware that something is ‘not quite right’. In the present study participants responded to this noticing in a number of ways, notably comprising activities such as ‘justifying’, ‘disagreeing’ and ‘hiding’. The concept of ‘justifying’ resonates with the idea of ‘normalising’ that Keady developed in his research. According to Keady both carers and the person with dementia initially dismiss the behaviour that they have ‘noticed’ by ‘normalising’ it and applying plausible explanations for its occurrence (I’m unwell, I’m stressed at work etc) based on this they can support the perception that ‘this is OK’. Justifying served a similar purpose in this study.

‘Hiding’ activities were also identified in Keady’s (1999) study, when it was employed to describe the efforts of the person to ‘hide’ their difficulties from others. In the presented study ‘hiding’ was utilised both by the person with AD and the family carer. In the latter case it was mainly adopted by partners of the person with AD the aim of avoiding worry for other members of the family, generally their children. This finding again highlights the importance of including the wider family as it provides for a more complete and nuanced understanding of processes that have previously been described in a dyadic context. Later in the present study the family as a whole also adopted a form of ‘hiding’ in that they did not tell their relative that they had AD, usually because they thought that this was both pointless (as there is no cure) and that it would impact negatively on their relative’s self-esteem. Therefore whilst this was done with the best of intentions it nevertheless meant that the person with AD could not make fully informed choices.

In addition this study suggests that ‘noticing’ is *‘a recurrent process that helped inform the act of caring*’ rather than merely a first stage in the caregiving experience. However the nature of what was noticed changed over time and later the largely passive act of ‘noticing’ changed to a more active form of observation termed ‘watching’.

‘Watching’

As the study findings suggest family caring at the early stage of the disease does not involve the provision of direct physical care, rather more subtle forms of activity are in evidence. One such, a more active form of observation than ‘noticing’ is ‘watching’. This primarily entails observing the person with AD closely and ‘keeping an eye on’ his/her activities and behaviours, initially in a discrete and unobtrusive manner. This can be seen as akin to the ‘increased vigilance’ described by Keady (1999). Although this ‘watching’ did not involve hands-on care it was acknowledged as being stressful and demanding by relatives as many feel constantly on edge, and ‘watching’ became their overriding concern

The existence and importance of such ‘invisible’ dimensions of care has, as noted earlier, already been suggested by Bowers (1987) in her work exploring the meaning and purpose of care from the caregiver’s perspective. She found that caring is much more complex than providing practical assistance to the person and that much of the stress of caring is unrelated to ‘instrumental’ care. This was reaffirmed in the present study. What is more, the purpose of ‘watching’ in this study resonated with distinct types of care that Bowers outlined in her work, specifically ‘preventive’ and ‘protective’ care.

For Bowers (1987) ‘preventive’ care comprised mainly monitoring the person at a distance. This closely corresponds with those families who adopted a ‘watching’ brief in this study, for example discretely following the person with AD when they walked to church to see that they didn’t get lost. However as the condition progressed and further changes occurred it was not possible for the family to maintain this distant ‘watching’ any longer. Therefore ‘watching’ became a more overt activity that it was quite difficult to keep from the person with AD. This then could have been seen to mirror the ‘supervisory’ care described by Bowers.

However, this study adds the reciprocal element of the caregiving relationship that Bowers failed to account for in her work (she only interviewed caregiving daughters), by recognising the response of the person with AD to this supervisory dimension of care. In many cases the person still lived a relatively independent life and wanted to maintain their usual routines. Therefore sometimes they felt that being ‘watched’ by their relative was an imposition and that their relative ‘*doesn’t let me breathe’*. Paradoxically this perceived overcontrol by the family tended to increase the ‘hiding’ behaviours of the person with AD, and as consequence the family redoubled their ‘watching’ efforts and the potential for a ‘vicious’ circle emerged. Maintaining a balance between ‘watching’ the person and not exerting too much control clearly resulted in difficulties for the family. Excessive control served to constrain the person and make him or she feel disempowered, whereas watching for the carer was important for their peace of mind.

In addition to this ‘preventive’ dimension of care, a protective element, dimension with the goal of maintaining the self-esteem and image of the person with AD as long as possible, was evident. Again this clearly resonates with Bower’s (1987) much earlier idea of ‘protective care’. However in the context of this study the notion of protection was not unilateral, from the caregiver to the person with AD, but also extended to different interactions within the family, such as the protection of the caregiver towards other family members aimed at avoiding to unnecessarily worry for them or the protection of the person with AD toward the caregiver or other members of the family for a similar reason.

The anticipatory aspects of care originally described by Bowers (1987) and later elaborated on by Nolan et al. (1996) also figured in this study, particularly in relation to *‘looking at future’*. This involved both asking ‘*what would happen if…?* as described by Bowers, and *‘what will happen when…*? as suggested by Nolan et al. this study illustrated how some families tended to adopt a day-to-approach, and did not think too far ahead, just as described by Hellström et al. (2007), whereas other families tend to dwell on the future and play out a range of possible scenarios. The latter approach tend to result in greater stress and anxiety as carers were engaging in the type of ‘speculative anticipation’ described by Nolan et al. (1996) when the carer has little information as opposed to ‘informed anticipation’ which occurs when the carer has adequate advice, information, and support to allow for informed choice. In most cases in this study families tended to ‘over-anticipate’ possible events and were therefore ‘living in fear of future’ rather than enjoying the present. Again this is an area where appropriate help and support could do much to improve matters.

‘Redefining’

The second stage of the model *‘our life is changing’,* illustrates how, by engaging in a process of ‘watching’, the family became more aware of the changes that were occurring in their lives. Data suggest that family life is affected in fundamental ways and this leads individuals needing to ‘redefine’ certain aspects of their roles, relationships and every routine. This finding is consistent with the work of Canga (2011) and her notion of 'a change in life' developed from her study of the experience of Spanish families in the transition to dependency of an older relative. She found that the caring experience created new demands and responsibilities in families caring for a dependent older relative which affected the lives of all family members involved. This author identifies the high cost that this ‘change in life’ means to the family and specifically the physical, emotional and even economic burdens it entails. While the negative impact of such changes is well documented, this study failed to recognize the ways in which families can adapt to changes and experience potentially outcomes. In my study how successful families are in ‘redefining’ of certain aspects of family life influences the perception of caring as largely a problematic experience or alternatively as an opportunity for family growth. The ‘redefining’ style of the family is shaped largely by the type, quality and nature of existing family relationships and ways of working together. The data suggested that tensions and challenges between the need to maintain family balance and to redefine the way the family works in the context of AD occurred in all families. In some cases these challenges were resolved and this brought the family closer together with positive consequences while in others instances this was not possible and families felt lost, and did not know how to resolve either the problems they perceived themselves to face or their reactions to them. Parallel to Canga’s (2011) idea of families ’negotiating conflicting feelings’, some families in this study failed to do this and consequently could not find an appropriate ‘balance’ in their situation, in order to response to the newly ‘defined’ family caring situation.

‘Balancing’

The third stage of the model ***‘**keeping things together’* revolves around the basic social process of ‘balancing’. This describes the way families work (or do not) to preserve and create a balance between caring and preserving a semblance of life as it has been before the onset of AD. The study illustrates that families who find balance are better able to integrate living with AD into their lives whilst maintaining close family dynamics. In contrast families that fail to find balance struggled ‘against’ the AD and this caused, or exacerbated, family conflict. From a related perspective Canga (2011) delineates what she called ‘Sustainable Caring Families’ (which mirrors the ‘family-care in balance’ in this study) as opposed to families that become ‘Dependent of the dependent’ (mirroring the ‘family-out of balance’ in my study).

In her study Canga (2011) argues that certain families are able to combine care with other important aspects of their lives without exhausting their physical, emotional, economic, family and personal resources. In doing so they may experience some purpose and satisfaction. Conversely she found some families who became immersed in caring, where the dependent person and their needs become the centre and axis of their family life, thereby defining the family. She argues that appropriate and timely support services directed at the whole family may help these caring families to move towards 'Sustained caring family ’rather than toward the development of 'dependency on the dependent person'. This of course is likely to be very challenging in practice, especially in circumstances where prior family dynamics have historically been poor, this provides a very difficult ‘past’ on ‘which to build’ (Keady, 1999).

Overall the three stage model and the processes developed in this study reinforce the evolutionary and dynamic nature of caring in AD. As has been argued in the literature family care this is not a static commitment but an active process that varies over time. Temporal models of care, particularly in dementia, have been already developed (see for example Bowers, 1988; Wilson, 1989;

Willoughby and Keating, 1991; Keady and Nolan, 1994) although these have mapped principally the caregiver experience over the course of the condition. Keady (1999) included both the caregiver and the person with dementia and integrated both perspectives to illustrate the dynamics of dementia. Nevertheless this was created from separate perspectives so failed fully to address the interactions that this study has shown occur within the family.

More recently there have been a number of studies that have focussed on the concept of ‘couplehood’ in dementia (See Hellström et al., 2007 for a review) and whilst these have looked more closely at the interaction of couples over time by definition this has been from a dyadic perspective.

In contrast the model presented here emerged from data gathered using a family systems approach that sought to include the accounts of various members of the family, not only the main caregiver and the person with AD. This approach provided valuable insights into the interactions that occurred among different members’ experiences of living with AD. Such interactions that would have not been possible to be capture if only individual interviews were conducted. This model therefore represents a starting point for a different approach to understanding how families live with AD and the need for professional support.

Although exploring such support was not an original goal of the study the overriding theme that emerged across all the three stages of the model *‘feeling abandoned’*, captured the experiences that families had in their contact (or more accurately, no contact) with professional support services at different stages of the process. The importance of countering this perception of *‘feeling abandoned’* by providing more adequate and tailored support is one of the key implications of the study that will be considered in more detail below. However it goes beyond differing forms of support and calls into question the whole approach to supporting frail older people and those who provide them with the majority of the help that they need; the family.

8.2 Challenging Traditional Care Models: Towards a Family System Approach to Living with AD

Living with AD, as with many other long term conditions, represents a vital transition for the whole family unit (Kurz and Shepard, 2005). It often entails a new and stressful situation that in most cases interrupts the existing logic of family life, leading to potential crisis. This study has provided evidence that the onset of something such as AD often does not allow the family to plan or rehearse options and consequently there may be considerable imbalance, confusion, and distress until the family establishes new patterns of roles and responsibilities, relationships, future expectations and everyday life. However despite such challenges the experience can have be a positive and rewarding one enhancing commitment, personal growth, affection and solidarity among family members. As the study findings revealed some families were able to perceive the caring experience as an opportunity to discover and strengthen family talents and abilities, to remain close to each other and increase the sense of family commitment. For others the opposite happened. Therefore, transforming this experience into one promoting well-being, including for the person with AD, can be highly beneficial and reinforce, if appropriate, the family's desire to continue caring for their loved one to the best of their ability (Canga, 2011; Quinn et al., 2012).

As in any other vital transition the family needs time to assimilate and adapt to their new situation (Kurz and Shepard, 2005). Consequently, professional support is needed as early as possible, taking into account the family's perception and understanding of the disease and the resources that they both have and need. Promoting a spirit of cooperation, open communication and negotiation among family members is paramount to achieving this (Lilly, 2005).

This means making the family the unit of assessment and intervention in AD care. Professionals need to focus more on family interactions and relationships when living with AD, and others long term conditions, as has been argued for some time (Rolland, 1984). Helping the family unit to work on their relationships and communication patterns is an essential element of the support they need if problems are to be both prevented and addressed (Wright and Leahey, 2005).

At the moment however the policy discourse around dementia care is primarily couched in terms of person-centred care, although initiatives such as dementia friendly communities are being promoted in some countries, such as the UK (Joseph Rowntree Foundation, 2014). Others have, for some time, called for a relationship centred approach which recognises the needs of people with dementia, family carers and formal service providers (Nolan et al., 2002). This would suggest a need to re-orientate the current focus of interaction.

Professionals, with specialist education in dementia, should be key players in working proactively with the family as a whole to develop rational, evidence-based responses from the very beginning of the journey of living with AD. Working with the family on its communication is central in assisting members to define and clarify problems, solve potential conflicts, set limits, and clarify boundaries and family roles (Lilly, 2005). Bringing the family together to discuss the care process and make mutual expectations transparent will help to create optimum conditions for everyone to feel that their perspective is being considered (Wright and Leahey, 2005). Through working in partnership with the family, maintaining meaningful conversations, inviting people to talk about what they know, feel and think about AD and the caregiving role, professionals can help the family to explore their meanings, values and beliefs and determine which strategies best suit each family (Lilly, 2005). Encouraging such family discussions from the time of diagnosis, when caregiving families often struggle to understand the situation can help to prevent potential problems arising at the outset (Wright and Leahey, 2000), which can be a critical to family adjustment throughout the whole experience (Quinn et al., 2010). To establish a therapeutic alliance between families and professionals it is necessary to view the family as a system, with potential strengths and resources, rather than as individual victims who need to be rescued (Lilly, 2005; Canga, 2011).

Professionals should seek to build on the skills, values and hopes of the family, and create a perception of caring as being a time of potential opportunity for further family growth and development (Peacock et al., 2010; Skerrett, 2010). Central to this is highlighting what families are doing well, stimulating meaningful discussion and recognising existing strengths and resources, rather than, as present, letting these be overshadowed by the difficulties families face (Wright and Leahey, 2005). The following have been suggested as ways of helping the family to set realistic goals in the face of AD (Lilly, 2005):

- Begin by obtaining the family's understanding of the condition
- Explore each member's perception of what AD means
- Family priorities, both as individuals and as a group, should be established and discussed. These might include financial concerns, time constraints and generational responsibilities.
- Help the family to establish caregiving goals that are realistic and acceptable. Help them to identify existing family values, beliefs, strengths and resources.
- Advise them on how they can plan to 'work together'.
- Day-to-day care expectations should be made explicit (responsibilities of individuals, emergencies and other contingencies)
- Provide education on the illness and the caregiving role.

Families do not expect immediate solutions but value support in order to keep going and live with AD. Both people with AD and their families need support to help them maintain their lives, as individuals and as part of the family. Hence the challenge for health care professionals is to help families preserve their identity, despite the challenges of the disease and to continue their own family project, through promoting autonomy and decision-making from the beginning (Canga, 2011). It is important to encourage families to be creative when facing crises, to cope with persistent tensions and to react positively to future challenges, knowing that they are supported if need be (Canga, 2011).

As noted above for this to happen there needs to be a change in emphasis in the current direction of policy and practice. It has been suggested for some time that formal support should be provided in the context of a non-judgmental relationship between the family and professionals, based on a collaborative and nonhierarchical relationship (Hutchfield, 1999). According to Nolan et al. (2003), professional carers should acknowledge family' understanding of the situation, and, where appropriate, took action. Mutual respect lays the foundation for a trusting relationship and the development of fruitful partnerships. Recently Dewar and Nolan's (2012) have promoted the concept of compassionate relationship centred care, based on 'appreciative caring conversations' that allow both professionals and families to gain '*personal and relational knowledge'* about *'who they are and what matters to them*' and '*how all of them feel about their experience'*. Adopting such a perspective would promote active involvement of the whole family in the way support services and care plans are designed and delivered. As Rolland (1984; 1988) has argued for some time responding to the challenge of long-term conditions requires that we forge partnerships between families, including the affected individual, formal service systems, and the particular challenges posed by diverse long term conditions. He terms this the 'therapeutic quadrangle' and this would seem to provide a solid basis for a meaningful societal response to the future challenges to health and social care systems face.

Having set the study findings into a larger context, both in terms of the wider literature and policy, attention is now turned to the potential implications of the study, especially in Spain.

8.3 Implications of the Current Study

8.3.1 Implications for Policy

The current Alzheimer's care model in Spain does not recognize the State as primarily responsibility for the care of people with AD. This model considers it as a shared responsibility with the family, with the primary role being with the latter. The study findings have demonstrated that the whole family is affected by the consequences of AD. This is consistent with the findings of various studies cited throughout this thesis. What is abundantly clear from the present study is that, at least for these families, that they *'feel abandoned'* when living with the early stages of AD. This study, along with the literature, mandates that health care policies should focus on the quality care of families living with this condition. It is therefore essential that health care policies and practices ensure that people with AD and their families receive the necessary support over the course of the condition, beginning at point of first contact.

The model developed together with the families, may inform the design of policy, by the Ministry of Health and other government organizations and regulatory bodies in Spain, to improve the quality of life of families living with AD. This study is fully consistent and serves to reinforce the development of a National Alzheimer's Plan for Spain, which embraces an integrative care model, including the person and the family, and requires action on several fronts. Specifically, it will require health and social care services to increase investment in educational programmes and strategies for professionals (see below), as an essential component of improving family care support services.

Additionally policies must take a proactive, rather than a reactive stance, to working in partnership with families with early contact, on-going evaluation of the support provided and adequate follow-up to ensure that families have the resources that they need. Preventing family difficulties that may arise as a consequence of the condition and the demands it makes are likely to contribute to reduce health and social care costs, and, importantly, the opportunity costs on family's lives. Prevention is not only ethically supportable but is likely to be more cost-effective than intervening once there is an unsustainable caring situation and the family 'balance' has been lost.

8.3.2 Implications for Practice

The study findings provide new insights that may help inform better services and support strategies for families caring for older people with AD and develop new strategies built on the strengths the family has and the circumstances in which they live. This will require significant changes to current practice. In particular it will require a fundamental shift in the ways that professionals see their role. Rather than being the 'experts' who dispense knowledge, as Nolan and colleagues (Nolan et al., 2006) suggest, they will need to become facilitators who work in partnership with families as ‘co-experts’. This is likely to be particularly challenging for certain groups of professionals who historically have perceived their role in fundamentally different ways. Wholesale culture shift will be needed and this is a long term agenda but if the type of policies suggested above are introduced this will provide an obvious stimulus.

In the short term the typology of family dynamics that has been developed has the potential to inform clinical practice and the design of support strategies on the basis of the needs of particular families. It is clear that families with a close existing relationship do not approach the situation in the same way that families with long-standing conflicts do. Thus the motivation to commence and continue caring for their loved one differs. Including such factors in assessment and planning of support should become a key part of practice. Moreover practitioners need to engage with families at the earliest possible point and work with them in a proactive and on-going fashion, providing practical advice and information as well as emotional support. Balancing the needs of the whole family, with those of individual members, including the person with AD, is an essential but delicate undertaking.

In addition to the above the three-stage model provides a framework for professional assessment and intervention by facilitating the understanding of the processes that take place in the family while living with early stage AD. It is argued that services should be 'stage specific', tailored to needs at varying times in the AD experiences. Despite each family situation being unique, there are broad stages and processes which may help predict the occurrence of certain types of needs. These can guide the way care is planned and delivered. For example:

- The general dissatisfaction families reported in obtaining the diagnosis suggests that improving the timeliness of diagnosis is an important objective for health care providers in the Spanish context. Traditional models of assessment are often too ritualistic and narrow, focussing on concrete symptoms and problems rather than the personal and family experiences, which are often overlooked or dismissed. This needs to be addressed.

- Much more needs to be done to make people aware of the signs and symptoms of AD so they can seek help and get access to timely diagnosis, treatment and support. The study findings suggest that activities such as ‘justifying’, ‘hiding’ and ‘disagreeing’ may contribute to delay in getting the diagnosis. Families sometimes wait too long before going to the doctor and when they do their concerns are not considered fully. Actions to address this are needed.

- Data suggested that families are ‘left to get on with it’ once they received the diagnosis, rather than being helped to plan proactively. A more comprehensive and detailed approach needs to be adopted, such as that discussed above in which the focus moves from individuals to the family as a whole.

- The poor initial contact with services was mirrored thorough out much of the early stages. No real help was provided to assist the family organize and redefine family life. Professional interventions that help family to be aware of and explore processes such as ‘redefining’ and ‘balancing’ may prevent family conflict and promote family unity.

All of the above suggest the need for new approaches to education**.**

8.3.3 Implications for Education

If a relationship and family centred approach is to be implemented this will have significant implications for professional practice and education that moves far beyond traditional curricula and methods of delivery at both qualifying and post-qualifying levels. The study findings offer guidance for the content of future courses and curricula based on a family system approach that consider the skills and competences that professionals require to implement such a model. This should include integrating the lived experiences of people with AD and their families into training for health and social care staff so that practitioners are able to develop more effective strategies and care plans that address only the needs whole family.

Spanish health care education has been primarily focus on the assessment, planning, implementation and evaluation of services to individuals. However as health care demands are changing it is essential that staff to see individuals as part of the wider family. For this reason it is necessary to provide health care staff with conceptual frameworks, such as Family System Nursing, to work with families living with AD, and similar long term conditions. In particular professionals need to be more aware of and attuned to the 'invisible' dimensions of care, seen as so important by the families. The present findings may make a modest contribution in this regard.

Living with AD is a challenging, ongoing, and shifting process for families, and professionals have to be aware of the evolving and transformative nature of the care process as well as the family dynamics so that they can be supportive and contribute to family well-being and harmony. The study findings, especially the typology and temporal model that were developed, could be included in Family Nursing curricula, offering a framework to inform the education of future and current nurses. This would encourage them to focus on the whole family as the unit of care in Alzheimer's disease and enable the development of meaningful relationships between families and nurses. The theoretical concepts and the different stages identified in this thesis provide a means by which nurses can assess the impact of AD on the family throughout its trajectory. According to Wright and Bell (2009), embracing the belief that 'illness is a family affair' could change the face of nursing practice if fully adopted by nurse educators. Both theoretical courses and clinical practice with families should provide nurses with more specific skills to address family dynamics and better understand family processes such as *watching*, *redefining* and *balancing.* This would enable nurses to reduce potential distress and promote family healing when living with AD. Yet in Spain there is no specific content in nursing curricula on family dynamics, family nursing frameworks and family assessment models. It remains the case that family heath is approached in a tangential way and is not considered in depth (St John and Rolls, 1996; Duhamel, 2010).This needs to change.

In contrast the Faculty of Nursing at the University of Navarra has introduced a family nursing framework into the curriculum of undergraduate (as an optional subject named 'the family as the unit of care') and graduate nursing studies (advance practice nursing with families).Therefore the finding of the study can be integrated into these courses to expand the theoretical knowledge about families living with chronic conditions, particularly Alzheimer's disease.

The widespread dissemination of the study findings in a range of formats is necessary so that healthcare professionals, managers and policy makers can access them easily. This is important as the family systems approach has rarely received attention in research, practice and even less in education within the Spanish context. Additionally to ensure that families and the public in general have access to the study results different approaches will need to be taken, for instance:

- Placing them on dementia websites, especially those designed to support families and people with this condition, such as the website of the Association of Relatives of people with Alzheimer of Navarra. Similarly on popular websites designed and implemented by public agencies such as the Government of Navarra, the Spanish Institute of Older People and the Spanish Virtual Centre on Ageing among others. This will make the results more accessible to the wider population.
- Publishing them in popular journals or magazines;
- Creating pamphlets for use in community health-care services;
- Distributing them to people and families in workshops or small group sessions given at services such as local Alzheimer's Associations and Memory Units;
- Disseminating them through other types of mass media, e.g. TV, radio, newspaper.

Implications for Family Education

The study findings have also the potential to be used in training the family to live with AD in as positive a way as possible. The model developed may be used to produce information, advice and guidance for families that enables them to take care of their relative with AD without losing the balance of their lives.

The study findings may inform the development of educational intervention, following methods such as the PREP model (Archbold et al., 1995), originally developed for caregivers, but equally applicable to the whole family, to increase its preparedness and competence, enrich the caring experience and make the future more predictable. This study suggests areas where greater knowledge and expertise is required to help the family achieve balance rather than increasing stress and conflict.

8.3.4 Implications for Future Research

The findings of this study suggest some important areas for further investigation into family care. For instance,

- Exploring further the AD experience of the whole family unit over time to provide in-depth insights into the impact of AD in a context of varying family relationships. This study has revealed that intergenerational relationships including adult children-parents significantly affect the AD experience. However it was limited to the early experience alone and needs to be extended beyond this. As family dynamics and circumstances have been shown to change over time, as new challenges emerge and new types of care are developed. As AD has a progressive and changing nature, more longitudinal studies of its impact on the family unit are required.

- In this study people with AD were recruited early in their experience so their involvement and participation in the study was not as great a challenge as it might be in later stages. However, if there is a disproportionate inclusion of people with early stages AD in research, which is not balanced by the inclusion of those in more advanced stages, this may result in a lack of understanding of issues of relevance to people and families in the more advanced stages with a consequent lack of equity and a failure to address their real needs (Alzheimer Europe, 2011). Dementia diagnosis is no longer a sufficient reason to exclude people from taking part in research projects

(Hubbard et al., 2003; Dewing, 2007; Hellström et al., 2007). Furthermore involving people with such a condition in all aspects of research is increasingly recognised as being essential to good research (Alzheimer Europe, 2011) Therefore future research designs will need to consider the best way to include people in later stages of the condition, as their experiences are paramount in order to adapt care and support services appropriately.

- There is a need to extend the study to families that live in other areas, particularly in rural areas where access to services is more difficult and the development of family care in AD can vary. Similarly exploring the family experience of AD with families not only in their own homes but also in other community services such as residential accommodation is also recommended since, the family continue caring for their loved ones and decisions regarding support resources may also affect the entire dynamic of the family.

- More empirical and theoretical work is required to further develop the typology and the theoretical model that emerged from the study. Its relevance should be explored in diverse caring circumstances, as well as being compared with other theoretical models to expand and enhance its usefulness.

  Since this model is based on a family system approach it would be useful to contrast it with other theoretical models in the area of family nursing. For instance a recent study conducted by Arestedt et al. (2015) about the family experience of living with chronic diseases, and the influence of their illness beliefs concluded that holding certain beliefs may help the family to accept the condition as either *' part of life'* or as *'a threat to life'*. According to Walsh (2006) and Wright and Bell (2009) our culture affects our beliefs, and these in turn our influence our behaviour. Therefore, certain beliefs may predispose the family to live one way or another with a long-term condition, and as this study suggested, the result may mean living in either balance or conflict. Clearly the former is preferable and further development of the theory underpinning this study might do much to help nurses work more effectively with families.

Systematically and rigorously comparing the model and study findings described here with others from the family nursing field would hopefully result in fuller elaboration of key family processes that can be applied to a wider range of long term conditions.

- Similarly it is necessary to undertake ‘translational research’ where the theoretical knowledge is transferred to clinical practice, and the effectiveness of any interventions is assessed. This will serve to further understand the issues and intricacies surrounding the implementation of a family systems approach in care and the relevance of temporal models of the AD experience in clinical practice.

- This study took an explicitly family focussed approach as an underpinning principle. However, if the above translation into practice is to be achieved then studies are needed that explore the perspectives of professionals and service providers on current experiences of delivering support in dementia care. Only in this way will a truly holistic picture emerge.

8.4 Limitation of the Research and Reflections for Future Studies

When accessing families some challenges in implementing a whole family approach were experienced. For instance, theoretical sampling directed data collection with wider members of the family, however interviewing all of the members involved in the experience was not always possible. This was particularly the case of families in which there was a pattern of deep-rooted towards certain family members. Some relatives acted as a barrier to their full involvement and therefore their views could not be heard. Similarly the presence of conflicting dynamics in some families restricted the inclusion of all parties. Therefore a range of challenges to accessing and interviewing the ‘whole’ were identified including internal family dynamics, geographical distribution of family members and ethical concerns about coercion or privacy. Therefore, although the ‘whole’ family approach was the aim, inevitably each family decided, collectively and individually, how this was determined. It would be advisable in future work to maintain the flexible approach to recruitment and data collection that was taken in this study so that families decided and choose to get involve and work together, individually or a combination of the two. This is perhaps an inherent limitation of such an approach and of course suggests that similar problems are likely to be encountered by practitioners seeking to adopt this approach.

Another limitation, or at least challenge, of a study of this nature is around the use of the word 'Alzheimer's and the effect this might have on the types of discussion that are possible. As explained in the methodology chapter all potential study participants received a detail explanation of the study purpose and processes. In addition written information about the research was provided to both the person with AD and their families. In both the information sheet and the written consent form the word 'Alzheimer´s disease' was not included. Rather the term 'memory loss' was used in order to avoid potential harm to any person who was not aware of, or did not want acknowledge, the diagnosis. Likewise, during the interview process the use of 'Alzheimer`s disease' term was avoided unless the participants chose to use it openly. A few participants (relatives) used the term but most of them used phrases such as 'loss of memory', 'forgetfulness episodes', 'and 'slips and lapses'. Supporting this was of course is the only ethical stance to take.

Nevertheless use of the term 'memory loss' may have some limitations as it places emphasis on only one aspect of living with the condition and may, unwittingly result in a rather narrow perspective emerging. In this regard, a reductionist view of what AD means and implies may prevent a full understanding and awareness of the condition by the family and the person from emerging. Suffering from AD does not only mean forgetting things, events and people. The alteration of high cognitive function such as memory also entails difficulties with language, executive function and spatial organization among others. Referring to AD as suffering from 'memory loss', without further explanation of what it involves, may give rise to a overly simple representation of the lived reality.

Finally, participating families in this study were recruited through a reference centre for supporting people with cognitive problems and neurological disorders in Navarra, specifically from the memory unit programme targeted at people with early stage cognitive disorders. Although the common practice is that patients from the Neurology Service of the Navarra's Public Health System are referred to this unit, there are some exceptions and not all patients reach such a service. This limited the number of potential participants recruited and the manner in which they were approached. In future studies it may be advisable to also recruit from community and local health care services (primary care) that have contact with people with AD and their families in order to expand the numbers and type of potential participants.

8.5 Conclusions

This study aimed to explore the family experience of early stage AD, adopting a family systems approach and therefore including the person with AD and other members of the family involved. It is the first of its kind in a Spanish context

As well as extending knowledge and understanding it is hoped that the study results will contribute to the development of practical, educational and policy initiatives to enhance family systems care in AD, improve the quality of services and thus ultimately the quality of life the person and their relatives.

The findings of this study have described the social processes that take place in the family while living with AD. These offer new insights in the dynamics of the AD. In addition the study identified important factors that influence the way families respond to AD, especially the nature and quality of the dynamics preceding the AD experience, and how these impacts of the way families live with AD. Therefore the dynamic and reciprocal influence of AD on family relationships and the quality of the family AD experience was highlighted. The findings therefore contribute new knowledge about the subjective experience of AD and the family care process within a specific cultural context.

The study suggests the need for a number of significant changes and improvements to AD care and support services in the Spanish context, in order to prevent families 'feeling abandoned' and that they are living with this condition alone. A fundamental shift in the focus of practice, education, policy, and research is advocated, which adopts a much more inclusive vision of the AD experience from the beginning and considering the perspectives of all the individuals involved.

It is hoped that the present study, although conducted within a Spanish cultural context, also has wider relevance and implications in different settings and in relation to different conditions, especially those of chronic and disabling nature. At present, the healthcare system in Spain is immersed in a fundamental shift in its approach to long term conditions, including dementia. Underlying such a shift is the fundamental principle of empowering of individuals and their families to take charge of their health and care. If the theoretical model and the findings of the current study prove of some value in supporting such a shift then much will have been achieved.

REFERENCES

Abellán, A. and Esparza, C. (2010) Solidaridad familiar y dependencia entre las personas mayores. Madrid, Informes Portal Mayores.

Agarwal, M.R., Ferran, J., Ost, K. and Wilson, K.C.M. (1996) Ethics of informed consent in dementia research-the debate continues. *International Journal of Geriatric Psychiatry,* 11(9), 801-6.

Algado, M.T., Basterra, A. and Garriga, I. (1997) Familia y enfermedad de Alzheimer. Una perspectiva cualitativa. *Anales de Psicología,* 13(1), 17-29.

Ahmad, S., Orrell, M., Iliffe, S. and Gracie, A. (2010) GPs' attitudes, awareness, and practice regarding early diagnosis of dementia. *The British Journal of general practice*, 60(578), e360-5.

Allen, K.A., Fine, M.A. and Demo, D.H. (2000) *An overview of family diversity: Controversies, questions, and values*. In: D.H, Demo., K.R, Allen. and M.A, Fine (eds) *Handbook of family diversity*. New York, Oxford University Press. pp. 1-14.

Alloul, K., Sauriolb, L., Kennedyc, W., Laurierd, C., Tessiera, G., Novosele, S. and Contandriopoulosc, A. (1998) A Alzheimer's disease: a review of the disease, its epidemiology and economic impact. *Archives of Gerontology and Geriatrics*, 27(3), 189-221.

Alzheimer Europe (2011) *The ethics of dementia Research.* [online]. Alzheimer Europe. Available from: http://www.alzheimer-europe.org/EN/Ethics/Ethical-issues-in-practice/Ethics-of-dementia-research [Accessed at 30th May 2012].

Alzheimer Europe (2006) *Paris declaration*. Paris, Alzheimer Europe. Available from: http://www.alzheimer-europe.org/Policy-in-Practice2/Paris-Declaration-2006 [Accessed at 14th June 2011].

Alzheimer´s Disease International (2009) *World Alzheimer's report.* [online]. London, ADI. Available from: http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf [Accessed at 14th

June 2011].

Alzheimer Society (2010) *My name is not dementia People with dementia discuss quality of life indicators*. [online]. London, Alzheimer's Society. Available from: file:///Users/MacBook/Downloads/My_name_is_not_dementia_report.pdf [Accesed at 21st January 2011].

Ambert, A.M., Adler, P.A., Adler, P. and Detzner, D.F. (1995) Understanding and evaluating qualitative research. *Journal of Marriage and the Family*, *57*(4), 879-93.

American Psychiatric Association. (2000) *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. 4th edition. Washington, DC American Psychiatric Association.

Anderson, K.H. (2000) The family health system approach to family systems nursing. *Journal of Family Nursing,* 6(2), 103-19.

Anderson, G. (2004) Chronic *conditions: making the case to ongoing care. Partnership for solutions.* Baltimore, John Hopkins University Press.

Anderson, S.A. and Sabatelli, R.M. (1999) *Family interaction: A multigenerational developmental perspective*. Boston, Allyn and Bacon.

Andrén, S. and Elmståhl, S. (2005) Family caregivers' subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Science,* 19(2), 157-68.

Andrén, S. and Elmståhl, S. (2006) Relationship between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: A cross-sectional community-based study. *International Journal of Nursing Studies,* 44(3), 435-46.

Andrén, S. and Elmståhl, S. (2008) The relationship between caregiver burden caregivers´ perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing,* 17(6), 790-9.

Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H. and Whitlatch, C. (1995) *Profiles in Caregiving: The Unexpected Career*. San Diego, CA, Academic Press.

Annerstedt, L., Elmståhl, S., Ingvad, B. and Samuelsson, S-M. (2000) Family caregiving in dementia. Analysis of the caregiver's burden and "breaking point" when home care becomes inadequate. *Scandinavian Journal of Public Health,* 28(1), 23-31.

Arestedt, L., Benzin, E. and Persson, C. (2015) Families living with chronic illness: beliefs about illness, family and health care. *Journal of Family Nursing*, 21(2), 206-31.

Askham, J. (1997) *Supporting caregivers of older people: an overview of problems and priorities*. World congress of gerontology ageing beyond 2000: one world one future'. London, University of London, Age concern Institute of Gerontology.

Backman, K. and Kyngäs, H.A. (1999) Challenges of the grounded theory approach to a novice researcher*. Nursing and Health Science,* 1(3), 147-53.

Baker, C., Wuest, J. and Stern, P.N. (1992) Method slurring: the grounded theory/phenomenology example. *Journal of Advanced Nursing,* 17(11), 1355-60.

Beard, J.R., Biggs, S., Bloom, D.E., Fried, L.P., Hogan, P., Kalache, A. and Olshansky, S.J. (2012) *Global Population Ageing: Peril or Promise?.* [online]. Geneva, World Economic Forum. Available from: http://www3.weforum.org/docs/WEF_GAC_GlobalPopulationAgeing_Report_2012.pdf [Accessed at 14th May 2014].

Beaver, K., Luker, K. and Woods, S. (1999) Conducting research with the terminally ill: challenges and considerations. *International Journal of Palliative Nursing*, 15(1), 13-7.

Bell, J.M. (2009) Family Systems Nursing: Re-examined. *Journal of Family Nursing*, 15(2), 123-9.

Bengtson, V.L. (2001) Beyond the nuclear family: The increasing importance of multigenerational bonds. *Journal of Marriage and Family*, 63(1), 1-16.

Bell, J.M. (2009) Family Systems Nursing: Re-examined. *Journal of Family Nursing*, 15(2), 123-9,

Bermejo, F. (2004) *Aspectos familiares y sociales del paciente con demencia*. 2nd edition. España, Díaz de Santos.

Bernal, A. (2005) Entramado educativo de relaciones personales. En: A, Bernal (ed) *La familia como ámbito educativo*. Madrid, Rialp. pp. 119-44.

Bogenschneider, K. (2002) *Family policy matters: How policymaking affects families and what professionals can do*. Mahwah, NJ Lawrence Erlbaum.

Bouregeois, M.S. (2002) ‘Where is my wife and when am I going home?’ The challenge of communicating with persons with dementia. *Alzheimer’s Care Quarterly*, 3(2), 132-144.

Bowers, B.J. (1987) Intergenerational caregiving: Adult children and their aging parents. *Advances in Nursing Science*, 9(2), 20-31.

Bowers, B. (1988) Family perception of care in a nursing home. *The Gerontologist,* 28(3), 361-8.

Briggs, R. (1998) Caregiving daughters-accepting the role of caregiver for elderly parents. New York, Garland Publishing. p. 173.

Bringer, J.D., Johnston, L.H. and Brackenridge, C.H. (2004) Maximising transparency in a doctoral thesis: The complexities of writing about the use of QSR*NVIVO within a grounded theory study. *Qualitative Research*, 4(2), 247-65.

Brookmeyer, R., Corrada, M., Curriero, F. and Kawas, C. (2002) Survival following a diagnosis of Alzheimer disease. *Archives of Neurology,* 59(11), 1764-7.

Brown, J.W., Chen, S-L., Mitchell, C. and Province, A. (2007) Help-seeking by older husbands caring for wives with dementia. *Journal of Advanced Nursing,* 59(4), 352-60.

Bryant, A. and Charmaz, K. (2007) Grounded theory research: Methods and practices. In: A, Bryant. and K, Charmaz (ed) *The Sage handbook of grounded theory.* Thousand Oaks, CA, Sage. pp. 1-28.

Burgess, E.W. (1926) The family as a unity of interacting personalities. *The Family*, 7, 3-9.

Burns, A. and Iliffe, S. (2009) Alzheimer´s disease. *Brithish Medical Journal*, 338, 467-71.

Butcher, H., Holkup, P. and Buckwalter, I. (2001) The experience of caring for a family member with Alzheimer’s disease. *Western Journal of Nursing Research, 23*(1), 33-55.

Byszewski, A.M., Molnar, F.J., Aminzadeh, F., Eisner, M., Gardezi, M.A. and Bassett, R. (2007) 'Dementia diagnosis disclosure: A study of patient and caregiver perspectives'. *Alzheimer Disease and Associated Disorders*, 21(2), 107-14.

Cabrero, J. and Richart, M. (1996) El debate: investigación cualitativa frente a investigación cuantitativa. *Enfermería Clínica*, 6(5), 212-7.

Canga, A. (2011) *Experiences of the caring family in the transition of dependence of an older relative.* PhD thesis, University of Navarra.

Canga, A. and Vivar, C.G. (2013) La familia como ámbito de cuidado en la dependencia. In: A, Muñoz Fernández (ed) *El cuidado de las personas dependientes ante la crisis del estado de bienestar.* Valencia, Tirant lo Blanch. pp. 237-49.

Canga, A., Vivar, C.G. and Naval, C. (2011) Dependencia y familia cuidadora: reflexiones para un abordaje familiar. *Anales del Sistema Sanitario de Navarra,* 34(3), 463-9.

Carstensen, L. and Fried, L.P. (2012) The Meaning of Old Age. In: J.R, Beard., S, Biggs., D.E, Bloom., L.P, Fried., P, Hogan., A, Kalache. and S.J, Olshansky (ed) *Global Population Ageing: Peril or Promise.* Geneva, World Economic. pp 15-8.

Case Managements Society of America (2010) *Standards of Practice for Case Management*. Little Rock, AR, CMSA.

Caselli, R.J., Beach, T.G., Yaari, R. and Reiman, E.M. (2006) Alzheimer´s disease a century later. *Journal of Clinical Psychiatry,* 67(11), 1784-800.

Charmaz, K. (2000) Grounded theory: objectivist and constructivist methods. In: N, Denzin. and Y, Lincoln (eds) *Handbook of Qualitative Research*. 2nd edition. London, Thousand Oaks Sage Publications. pp. 509-35.

Charmaz, K. (2006) *Constructing grounded theory: a practical guide through qualitative analysis.* London, Sage Publications Ltd.

Charmaz, K. (2009) Shifting the Grounds: Constructivist Grounded Theory Methods for the Twenty-first Century. In: J, Morse., P, Stern., J, Corbin., B, Bowers., K, Charmaz. and A, Clarke (ed) *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA, Left Coast Press. pp.127-93.

Charmaz, K. (2014) *Constructing grounded theory: a practical guide through qualitative analysis. 2*nd edition. London, Sage Publications Ltd.

Clark, C., Chaston, D. and Grant, G. (2003) Early interventions in dementia: carer-led interventions. In: M, Nolan., U, Lundh., G, Grant. and J, Keady (ed) *Partnership in family care*. Philadelphia, Open University Press. pp. 33-49.

Clark, M., Reid, E., Morrsion, E., Capewell, S., Murdoch, L. and McMurray, J.J. (2008) The complex nature of informal care in home-based heart failure management. *Journal of Advanced Nursing*, 61(4), 373-83.

Cody, M., Beck, C., Shue, V.M. and Pope, S. (2002) Reported practices of primary care physicians in the diagnosis and management of dementia. *Aging and Mental Health,* 6(1), 72-6.

Cohen, C.A., Colatonio, A. and Vernich, L. (2002) Positive aspects of caregiving: rounding on the caregiver experience. *International Journal of Geriatric Psychiatry,* 17(2), 184-8.

Colliere, M.F. (2005) El arte de cuidar la vida. *Revista Rol de Enfermería*, 28(4), 266-8.

Connell, C.M., Boise, L., Stuckey, J.C., Holmes, S.B. and Hudson, M.L. (2004) 'Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians'. *The Gerontologist*, 44(4), 500-7.

Corbin, J. and Morse, J.M. (2003) The unstructured interactive interview: Issues of reciprocity and risks*. Qualitative Inquiry,* 9(3), 335-54.

Council of the European Union (2010) *Council conclusions "Innovative approaches for chronic diseases in public health and healthcare systems".* [online]. Brussels, The Council of the European Union. Available from: https://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/118282.pdf [Accessed at 14th March 2011].

Coyne, I. and Cowley, S. (2006) Using grounded theory to research parent participation. *Journal of Research in Nursing,* 11(6), 501-15.

Coyne, I.T. (1997) Sampling in qualitative research. Purposeful and theoretical sampling. Merging or Clear Boundaries? *Journal of Advanced Nursing*, 26(3), 623-30.

Cummings, J.L. and Cole, G. (2002) Alzheimer disease. *The Journal of the American Medical Association*, 287(18), 2335-8.

Cummings, J.L., Vinters, H.V., Cole, G.M. and Khachaturian, Z.S. (1998) Alzheimer's disease: etiologies, pathophysiology, cognitive reserve, and treatment opportunities. *Neurology*, 51(1), S2-17, S65-7.

Cutcliffe, J.R. (2000) Methodological issues in grounded theory. *Journal of Advanced Nursing,* 31(6), 1476-84.

De la Cuesta, C. (2009) El cuidado familiar: una revisión crítica. *Investigación y Educación de Enfermería*, 27(1), 96-102.

De la Cuesta, C. and Sandelowski, M. (2005) Tenerlos en la casa: The material world and craft of family caregiving for relatives with dementia. *Journal of Transcultural Nursing,* 16(3), 218-25.

De Pedro-Cuesta, J., Virués-Ortega, J., Vega, S., Seijo-Martínez, M., Saz, P., Rodríguez, F., Rodríguez-Laso, A., Reñé, R., Pérez de las Heras, S., Mateos, R., Martínez-Martín, P., Manubens, J.M., Mahillo-Fernandez, I., López-Pousa, S., Lobo, A., Reglà, J., Gascón, J., García, F.J., Fernández-Martínez, M., Boix, R., Bermejo-Pareja, F., Bergareche, A., Benito-León, J., Arce, A. and del Barrio, J.L. (2009) Prevalence of dementia and major dementia subtypes in Spanish populations: A reanalysis of dementia prevalence surveys, 1990-2008. *BMC Neurology*, 9, 55-63.

Denzin, N.K. and Lincoln, Y.S. (2000) *Handbook of qualitative research*. 2nd edition. Thousand Oaks, Sage Publications.

Denzin, N.K. and Lincoln, Y.S. (2005) Introduction: the discipline and practice of qualitative research. In: N.K, Denzin. and Y.S, Lincoln (ed) *The SAGE book of qualitative research*. 3rd edition. Thousand Oaks, Sage Publications. pp. 1-32.

Dewar, B. and Nolan, M. (2013) Caring about caring: developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, 50(9), 1247-58.

Dewing, J. (2007) Participatory research. A method for process consent with persons who have dementia. *Dementia,* 6(1), 11-25.

Dey, I. (1999) *Grounding Grounded Theory Guidelines for Qualitative Inquiry*. San Diego, Academic Press.

Diario de Navarra (DN) (2010) *Carmen y su vida con el Alzheimer.* [online]. Available from: http://www.diariodenavarra.es/20101207/navarra/carmenvidaalzheimer.html?not=2010120701475971&dia=20101207&seccion=navarra&seccion2=politica [Accessed at 19th September 2011].

Dubois, B., Feldman, H.H., Jacova, C., DeKosky, S.T., Barberger-Gateau, P., Cummings, J., Delacourte, A., Galasko, D., Gauthier, S., Jicha, G., Meguro, K., O´Brien, J., Pasquier, F., Robert, F., Rossor, M., Salloway, S., Stern, Y., Visser, P.J. and Scheltens, P. (2007) Research criteria for the diagnosis of Alzheimer´s disease: revising the NINCS-ADRDA criteria. *The Lancet,* 6, 734-46.

Duckworth, A., Steen, T.A. and Seligman, M.E. (2005) Positive psychology in clinical practice. *Annual Review of Clinical Psychology*, 1, 629-51.

Duhamel, F. (2010) Implementing family nursing: How do we translate knowledge into clinical practice? Part II: The evolution of 20 years of teaching, research, and practice to a centre of excellence in family nursing. *Journal of Family Nursing*, 16(1), 8–25.

Duran, P. (2013) Una lectura internacional de la dependencia. Su impacto en España. In: A, Muñoz Fernández (ed) *El cuidado de las personas dependientes ante la crisis del estado de bienestar.* Valencia, Tirant lo Blanch. pp. 59-91

Eloniemi-Sulkava, U., Saarenheimo, M., Laakkonen, M.L., Savikko, N., Kautiainen, H., Tilvis R.S. and Piftkälä, K.H. (2009) Family Care as collaboration: effectiveness of a Multicomponent Support Program for Elderly Couples with Dementia. Randomized Controlled Intervention Study. *Journal of the American Geriatrics Society,* 57(12), 2200-8.

Esparza, C. (2011) *Discapacidad y dependencia en España*. [online]. Madrid: Informes portal de mayores, nº 108. Available from: http://www.espaciomayores.es/InterPresent1/groups/imserso/documents/binario/pm-discapacidad-01.pdf [Accessed at 11st January 2012].

European Parliament (2008) *Written declaration on priorities in the fight against*

Alzheimer's disease. [online]. European Parliament. Retrieved from http://www.europarl.europa.eu/sides/getDoc.do?pubRef=//EP//NONSGML+WDECL+P6-DCL-2008-0080+0+DOC+PDF+V0//EN&language=EN [Accessed at 19th September 2011].

Eurostat (2013) *Eurostat regional yearbook*. [online]. Luxembourg, Publications Office of the European Union. Available from: http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-HA-13-001/EN/KS-HA-13-001-EN.PDF [Accessed at 27th January 2014].

Eurostat (2013) *Key figures on Europe 2013. Digest of the online Eurostat yearbook.* [online]. Luxembourg, Publications Office of the European Union. Available from: http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-EI-13-001/EN/KS-EI-13-001-EN.PDF [Accessed at 27th January 2014].

Eurosat (2014) *Basic figures on the EU. First quarter 2014*. [online]. Luxembourg, Publications Office of the European Union. Available from: http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-GL-14-001/EN/KS-GL-14-001-EN.PDF [Accessed at 14th March 2014].

Farran, C.J., Loukissa, D., Perraud, S. and Paun, O. (2004) Alzheimer's disease caregiving information and skills. Part II: Family caregiver and concerns. *Research in Nursing & Health,* 27(1), 40-51.

Farran, C.J., Gilley, D.W., McCann, J.J., Bienias, J.L., Lindeman, D.A. and Evans, D.A. (2007) Efficacy of behavioural interventions for dementia caregivers. *Western Journal of Nursing Research,* 29(8), 944-60*.*

Feeley, N. and Gottlieb, L.N. (2000) Nursing approaches for working with family strengths and resources. *Journal of Family Nursing*, 6(1), 9-24.

Feldman, H.H., Van Baelen, B., Kavanagh, S.M. and Torfs, K.E. (2005) Cognition, function, and caregiving time patterns in patients with mild-to-moderate Alzheimer disease: a 12-month analysis. *Alzheimer Disease and Associated Disorders,* 19(1), 29-36.

Ferrara, M., Langiano, E., Di Brango, T., De Vito, E., Di Cioccio, L. and Bauco, C. (2008) Prevalence of stress, anxiety and depression in Alzheimer caregivers. *Health and Quality of Life Outcomes,* 6(1), 93-7.

Ferrer, M.E. and Cinebal, L. (2008) El aprendizaje de cuidados familiares a pacientes con Alzheimer. Revisión bibliográfica. *Cultura de los Cuidados,* 23, 57-69.

Ferri, C.P., Prince, M., Brayne, C.H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P.R., Rimmer, E. and Scazufca, M. (2005) Global prevalence of dementia: a Delphi consensus study. *Lancet,* 366(9503), 2112-7.

Fitzpatrick, A.L., Kuller, L.H., Lopez, O.L., Kawas, C.H. and Jagust, W. (2005) Survival following dementia onset: Alzheimer's disease and vascular dementia. *Journal of Neurological S*cince, 15(229), 43-9.

Fitzpatrick, K.E. and Vacha-Haase, T. (2010) Marital Satisfaction and Resilience in Caregivers of Spouses with Dementia. *Clinical Gerontologist,* 33(3), 165-80.

Fried, L.P., Tangen, C.M., Walston, J., Newman, A.B., Hirsch, C., Gottdiener, J., Seeman, T., Tracy, R., Kop, W.J., Burke, G. and McBurnie, M.A. (2001) Frailty in older adult: evidence for a phenotype*. The Journals of Gerontology Series A: Biological Sciences and Medical Sciences,* 61(3), 262-6.

Friedman, M.M., Bowden, V. R., and Jones, E.G. (2003) Introduction to the family. In: M.M, Friedman., V.R, Bowden. and E.G, Jones (ed) *Family nursing. Research, theory and practice*. New Jersey, Prentice Hall. p.3-34.

Friedman, M. M., Bowden, V. R., and Jones, E.G. (2003). System theory. In: Friedman, M. M., Bowden, V. R., and Jones, E.G. *Family nursing. Research, theory and practice*. New Jersey: Prentice Hall. pp.151-65.

Gallicchio, C.W., Siddiqi, N., Langenberg, P. and Baumgarden, M. (2002) Gender differences in burden and depression among informal caregivers of demented elders in community. *International Journal of Geriatric Psychiatry,* 17(2), 154-63.

Gerrish, K. and Lacey, A. (2008) Investigación en enfermería. 5th edition. Madrid, McGraw-Hill.

Gibbs, G. (2002) *Evaluating the impact of formative assessment on student learning behaviour.* Newcastle, European Association for Research into Learning and Instruction Assessment Conference.

Gibson, W. and Brown, A. (2009) Working with qualitative data. London, Sage Publications.

Glaser, B.G. (1978) *Theoretical sensitivity.* Mill Valley, Sociology Press.

Glaser, B.G. (1998) *Doing grounded theory: issues and discussions.* Mill Valley, Sociology Press.

Glaser, B.G. and Strauss, A.L. (1967) *The discovery of grounded theory: strategies for qualitative research*. New York, Aldine.

Goldenber, I. and Goldemberg, H. (2000) Family Theraphy. An overview. Belmont, CA Wadsworth.

Government of Navarra, Health Department (2013) *Estrategia Navarra de atención integrada a pacientes crónicos y patológicos.* [online]. Comunidad Foral de Navarra, Departamento de Salud del Gobierno de Navarra. Retrieved from: http://www.navarra.es/home_es/Temas/Portal+de+la+Salud/Ciudadania/Nuevo+modelo+asistencial/Estrategia+navarra+de+atencion+integrada+a+pacientes+cronicos+y+pluripatologicos/ [Accessed at 27th January 2014].

Grant, G. and Nolan, M. (1993) Informal carers: Sources and concomitants of satisfaction. *Health & Social Care in the Community*, 1(3), 147-59

Grant, G., Ramcharan, P., McGrath, M., Nolan, M. and Keady, J. (1998) Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42(Pt 1), 58-71.

Green, J. and Thorogood, N. (2004) Qualitative methodology and health research. In: J, Green. and N, Thorogood (ed) *Qualitative methods for health research*. London, Sage Publication. pp 3-26.

Guba, E.G. and Lincoln, Y.S. (2005) Paradigmatic controversies, contradictions and emerging confluences. In: N.K, Denzin. and Y.S, Lincoln (ed) *The Sage handbook of qualitative research.* 3rd edition. Thousand Oaks Sage. pp 191-215.

Guillén, F. and Bravo, G. (2008) *Demografía del envejecimiento*. In: F, Guillén., J, Pérez del Molino. and T.R, Petidier (ed) *Síndromes y cuidados en el paciente geriátrico*. 2nd edition. Barcelona, Elsevier Masson. pp. 3-12.

Hallet, C. (1995) Understanding the phenomenological approach to research. *Nurse Researcher,* 3(2), 55-65.

Hamilton, H.E. (2008) Narrative as snapshot: Glimpses into the past in Alzheimer's discourse. *Narrative Inquiry*, 18(1), 53-82.

Hanson, E., Magnusson, L., Nolan, J. and Nolan, M.R. (2006) Developing a model of participatory research involving researchers, practitioners, older people and their family carers. *Journal of Research in Nursing,* 11(4), 325-42.

Harmon, H. (2005) Family health care nursing: an introduction. In: S.M., Harmon, V., Gedaly-Duff. and L, Rowe (ed) *Family health care nursing: theory, practice and research*. Philadelphia, F.A. Davis Co. pp. 3-37.

Harmon, S.M., Gedaly-Duff, V. and Rowe, J. (2005) *Family health care nursing*: *theory, practice and research.* 3rd Edition. Philadelphia, F.A. Davis Co.

Hellström, I., Nolan, M., Nordenfelt, L. and Lundh, U. (2003) Ethical and methodological issues in interviewing people with dementia. *Nursing Ethics*, 14(5), 608-19.

Hellström, I., Nolan, M. and Lundh, U. (2005) ‘We do things together’: a case study of ‘couplehood’ in dementia. *Dementia*, 4(1), 7-22.

Hellström, I., Nolan, M. and Lundh, U. (2007) Sustaining ‘couplehood’: spouses’ strategies for living positively with dementia. *Dementia*, 6(3), 383-409.

Henderson, S. (2002) Factors impacting on nurses’ transference of theoretical knowledge of holistic care into clinical practice. *Nurse Education in Practice*, 2(4), 244-50.

Hepburn, K., Lewis, M., Tornatore, J., Wexler, C. and Lindstrom, K. (2007) The savvy caregiver. The demonstrated effectiveness of a transportable dementia caregiver psycho education program. *Journal of Gerontological Nursing,* 33(3), 30-6.

Herrera, P. (1997) La familia funcional y disfuncional, un indicador de salud. *Revista Cubana de Medicina General Integral,* 13(6), 591-5.

Hogervorst, E., Barnetson, L., Jobst, K.A., Nagy, Z., Combrinck, M. and Smith, A.D. (2000) Diagnosing dementia: interrater reliability assessment and accuracy of the NINCDS/ADRDA criteria versus CERAD histopathological criteria for Alzheimer’s disease. *Dementia and Geriatric Cognitive Disorders*, 11(2), 107-13.

Hogervorst, E., Bandelow, S., Combrinck, M., Irani, S.R. and Smith, A.D. (2003) The validity and reliability of 6 sets of clinical criteria to classify Alzheimer’s disease and vascular dementia in cases confirmed post-mortem: added value of a decision tree approach. *Dementia and Geriatric Cognitive Disorders*, 16(3), 170-80.

Hoffman, F. and Rodriguez, R. (2010) *Informal Carers: Who takes Care of Them? Policy Brief. Vienna: European Centre for Social Welfare Policy and Research.* [online]. Available from: http://www.euro.centre.org/data/1274190382_99603.pdf [Accessed at 18th September 2011].

Hougham, G.W. (2005) Waste not, want not: cognitive impairment should not preclude research participation. *The American Journal of Bioethics*, 5(1), 36-7.

Hubbard, G., Downs, M.G. and Tester, S. (2003) Including older people with dementia in research: challenges and strategies. *Aging & Mental Health*, *7*(5), 351-62.

Hutchinson, S.A. (1993) Grounded theory: The method. In: P.L, Munhall. and C.O, Boyd (ed) *Nursing research: A qualitative perspective*. New York, National League for Nursing. pp. 180-212.

International Council of Nurses (2002) *Nurses always there for you: caring for families.* [online]. Geneva, ICN. Available from: http://www.icn.ch/images/stories/documents/publications/ind/indkit2002_part1.pdf [Accessed at 29th January 2014].

International Social Security Association (2010) *Cambios demográficos y seguridad. Desafíos y oportunidades.* [online]. Ciudad del Cabo, Foro Mundial de la Seguridad Social. Available from: http://observatorio.anses.gob.ar/archivos/documentos/OBS%20-%2000045%20-%20Cambios%20demogr%C3%A1ficos%20y%20seguridad%20social.pdf [Accessed at 3rd January 2011].

IMSERSO (2005) *Cuidados a las personas mayores en los hogares españoles. El entorno familiar.* [online]. Madrid, Instituto de Mayores y Servicios Sociales. Available from: http://www.imserso.es/InterPresent1/groups/imserso/documents/binario/cuidadosppmmhogares.pdf [Accessed at 11st September 2011].

IMSERSO (2008) *Las personas mayores en España. Datos estadísticos estatales y por comunidades autónomas (Vol. II).* [online]. Madrid, Ministry of Labour and Social Security. Available from: http://www.imserso.es/InterPresent2/groups/imserso/documents/binario/infppmm2008v2.pdf [Accessed at 11st September 2011].

IMSERSO (2009) *Las personas mayores en España. Datos estadísticos estatales y por comunidades autónomas (Vol I).* [online]. Madrid, Ministry of Health and Social Affair. Available from:

http://www.imserso.es/InterPresent2/groups/imserso/documents/binario/infppmm2008v2.pdf [Accessed at 11st September 2011].

Jani-le Bris, H. (1993) *Family care of dependent older people in the European Community*. Luxembourg, EU Publishers.

Jansson, W., Nordberg, G. and Grafström, M. (2001) Patterns of elderly spousal caregiving in dementia care: an observational study. *Journal of Advanced Nursing*, 34(6), 804-12.

Jicha, G.A. and Carr, S.A. (2010) Conceptual evolution in Alzheimer’s Disease: implications for understanding the clinical phenotype of progressive neurodegenerative disease. *Journal of Alzheimer´s disease,* 19(1), 253-72.

Jönsson, L. and Wimo, A. (2009) The cost of dementia in Europe: a review of the evidence, and methodological considerations. *Pharmacoeconomics*, 27(5), 391-403.

Jootun, D., McGhee, G. and Marland, G.R. (2009) Reflexivity: promoting rigour in qualitative research. *Nursing Standard,* 23(23), 42-6.

Kahana, E. and Young, R. (1990) Clarifying the Caregiving Paradigm. Challenges for the Future. In: D.E, Biegel. and A, Blum (ed) *Aging and caregiving: theory, research and policy*. New Bury Park CA, Sage Publications Ltd. pp 76-97.

Keady, J. (1996) The experience of dementia: a review of the literatura and implications for nursing practice*. Journal of Clinical Nursing,* 5(5), 275-88.

Keady, J. (1999) *The dynamics of dementia: A modified grounded theory study.* PhD Thesis, University of Wales.

Keady, J. and Gilliard, J. (1999) The early experience of Alzheimer's disease: implications for partnership and practice. In: T, Adams. and C.L, Clarke (ed) *Dementia care: developing partnerships in practice*. London, Bailliere Tindall. pp. 227-56.

Keady, J. and Harris, P. (2009) Editorial: family matters. *Dementia,* 8(1), 5-8.

Keady, J. and Nolan, M. (1994) “Younger onset dementia: developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers”, *Journal of Advanced Nursing*, 19(4), 659-69.

Keady, J. and Nolan, M. (2003) The dynamics of dementia: working together, working separately or working alone? In: M, Nolan., U, Lundh., J. Keady. and G, Grant (eds) *Partnerships in Family Care: Understanding the Caregiving Career*. United Kingdom, Open University Press.

Kennedy, T. and Lingard, L. (2006) Making sense of grounded theory in medical education. *Medical Education,* 40(2), 101-8.

Knapp, M. and Prince, M. (2007) *Dementia UK report: a report into the prevalence and cost of dementia prepared by the Personal Social Service Unit (PSSU) at the London School of Economics and the Institute of Psyquiatry at King´s College London, for Alzheimer´s Society.* [online]. London, Alzheimer´s Society. Available from: file:///C:/Users/pablo/Downloads/Dementia_UK_Full_Report-1.pdf [Accessed at 11th September 2011].

Koch, T. and Iliffe, S. (2010) Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC Family Practice*, 11(52), 1-8.

Koerner, A.F. and Fitzpatrick, M.A. (2004) *Communication in intact families*. In: A.L, Vangelisti (ed) *Handbook of family communication.* Mahwah, NJ, Lawrence Erlbaum. pp. 177-95.

Kramer, B.J. (1997) Gain in the caregiving experience: where are we? What next?. *The Gerontologist*, 37(2), 218-32.

Kurz, J.M. and Shepard, M.P. (2005) Families with chronic illness. In: S.M.H, Hanson., V, Gedaley-Duff. and J.R, Kaakinen (eds) *Family Health Care Nursing: theory, practice and research*. Philadelphia, F.A. Davis Company. pp. 413-35.

Kuzu, N., Beser, N., Zencir, M., Sahiner, T., Nesrin, E., Ahmet, E., Binali, C. and Cagdas, E. (2005) Effects of a comprehensive educational program on quality of life and emotional issues of dementia patient caregivers. *Geriatric Nursing,* 26(6), 378-86.

La Fontaine, J. and Oyebode, J.R. (2014) Family relationships and dementia: a synthesis of qualitative research including the person with dementia. *Ageing and Society*, 34(7), 1243-72.

Lach, H.W. and Chang, Y. (2007) Caregivers perspectives on safety in home dementia care. Western *Journal of Nursing Research,* 29(8), 993-1014.

Larizgoitia, A. (2004) *Services for supporting family carers of elderly people in Europe. Characteristic, coverage and usage. National background report for Spain.* Hamburg, Lit Verlag.

LeCompte, M.D. and Schensul, J.J. (1999) *Designing and conducting ethnographic research.* London, Sage Publications.

Lévesque, L., Ducharme, F., Caron, C., Hanson, E., Magnusson, L., Nolan, J. and Nolan, M. (2010) A partnership approach to service needs assessment with family caregivers of an aging relative living at home: a qualitative analysis of the experiences of caregivers and practitioners. *International Journal of Nursing Studies*, *47*(7), 876-87.

Lewis, A. (1992) Group child interviews as a research tool. *British Educational Research Journal*, 18(4), 413-21.

Lilly, M.L. (2005) Gerontological Family Nursing. In: S.M.H, Hanson., V, Gedaley-Duff. and J.R, Kaakinen (eds) *Family Health Care Nursing: theory, practice and research*. Philadelphia, F.A. Davis Company. pp. 375-92.

Lincoln, Y.S. and Guba, E.G. (1985) *Naturalistic inquiry.* Beverly Hills CA, Sage Publications.

Lliffe, S. and Wilcock, J. (2005) The identification of barriers to the recognition of, and response to, dementia in primary care using a modified focus group approach. *Dementia*, 4(1), 73-85.

Lloyd, V., Gatherer, A. and Kalsy, S. (2006) Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research*, 16(10), 1386-1404.

Lloyd-Sherlock, P., Mckee, M., Ebrahim, S., Girman, M., Greengross, S., Prince, M., Pruchno, R., Gutman, G., Kirkwood, T., O'Neill, D., Ferricci, L., Kritchevesky, S.B. and Vellas, B. (2012) Population ageing and health. *The Lancet,* 379(9823), 1295-6.

Long, T. and Johnson, M. (2007) *Research ethics in the real world: issues and solutions for health and social care.* London, Churchill Livingstone, Elsevier.

Losada, A., Peñacoba, C., Márquez, M. and Cigarán, M. (2008) *Cuidar cuidándose: evaluación e intervención interdisciplinar con cuidadores familiares de personas con demencia*. Madrid, Ediciones Encuentro.

Lyketsos, C.G., Colenda, C.C. and Beck, C. (2006) Position statement of the American Association for Geriatric Psychiatry regarding principles of care for patients with dementia resulting from Alzheimer disease. *American Journal of Geriatric Psychiatry*, 14(7), 561-72.

MacRae, H. (1999) Managing Courtesy Stigma: The Case of Alzheimer's Disease. *Sociology of Health & Illness*, 21(1), 54-70.

McCann, T. and Clark, E. (2003a) Grounded theory in nursing research: Part 1 – Methodology. *Nurse Researcher*, 11(2), 7-18.

McCann, T. and Clark, E. (2003b) Grounded theory in nursing research: Part 3 – Application. *Nurse Researcher*, 11(2), 29-39.

McConaghy, R. and Caltabiano, M.L. (2005) Caring for person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences,* 7(2), 81-91.

McGhee, G., Marland, G.R. and Atkinson, J. (2007) Grounded theory research: Literature reviewing and reflexivity. *Journal of Advanced Nursing,* 60(3), 334-42.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D. and Stadlan, E.M. (1984) Clinical diagnosis of Alzheimer's disease: report of the NINCDSADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's disease. *Neurology,* 34(7), 939-44.

Merton, R.K. (1968) On sociological theories of the middle range. In: R.K, Merton (ed) *Social theory and social structure*. New York, Free Press. pp. 448-58.

Mestheneos, E. and Triantafillou, J. (1993) *Carers talking: Interview with family carers of older, dependent people in the European Union*. Dublin, European Foundation.

Mestheneos, E. and Triantafillou, J. (2005) *Supporting family carers of older people in Europe. Empirical evidence, policy trends and future perspectives. The Pan European Background Report*. Hamburg, Lit Verlag.

Mills, J., Bonner A. and Francis, K. (2006) Adopting a grounded theory approach to grounded theory: implications for research design. *International Journal of Nursing Practice*, 12(1), 8-13.

Ministry of Labour and Social Affairs (2005) *Libro Blanco de la attention a las personas en situation de dependencia en España* [online] Madrid, IMSERSO. Available from: https://www.uab.cat/Document/580/416/LibroBlancoDependencia_01.pdf [Accessed at 11st September 2011].

Ministry of Labour and Social Affairs (2006) *Law on the promotion of personal autonomy and care for dependent person.* [online]. Spanish Government. Available from:

http://www.dependencia.imserso.es/dependencia_06/autonomia_dependencia/texto_ley/index.htm [Accessed at 11st September 2011].

Ministry of Health, Social Services and Equality (2012) *Estrategia para el abordaje de la cronicidad en el Sistema Nacional de Salud.* [online]. Madrid, Ministry of Health, Social Services and Equality. Available from: http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/pdf/ESTRATEGIA_ABORDAJE_CRONICIDAD.pdf [Accessed at 14th January 2014].

Moore, T.F. and Hollett, J. (2003) Giving voice to persons living with dementia: the researcher's opportunities and challenges. *Nursing Science Quarterly*, 16(2), 163-7.

Morse, J.M. (1998) Designing funded qualitative research. In: N.K, Denzin. and Y,S, Lincoln (ed) *Strategies of qualitative inquiry.* Thousand Oaks, SAGE Publications. pp. 56-85.

Morse, M. and Richards, L. (2002) *Read me first for a user's guide to qualitative methods.*Thousand Oaks, Sage Publications.

Navarra Statistical Office (2013) *Población de Navarra 1 de Enero de 2013.* [online]. Available from: http://www.cfnavarra.es/estadistica/confindex.asp?i=Informaci%F3n%2BEstad%EDstica&p=ie/indice2.asp?qry=01&d=ie/idx_izq.asp?qry=01&b=Informaci%F3n [Accessed at 14th March 2014].

Netto, N.P., Jenny, G.Y.N. and Philip, Y.L.K. (2009) Growing and gaining through caring for a loved one with dementia. *Dementia,* 8(2), 245-61.

Neufeld, A., and Harrison, M.J. (1995) *Reciprocity and social support in caregivers' relationships: Variations and consequences*. Qualitative Health Research, 5(3), 349-36.

Newcomer, R., Yordi, C., DuNah, R., Fox, P. and Wilkinson, A. (1999) Effects of the Medicare Alzheimer's disease demonstration on caregivers burden and depression. *Health Service Research*, 34(3), 669-89.

Nolan, M.R., Brown, J., Davies, S., Nolan, J. and Keady, J. (2006) *The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP)*. [online]. Report No 2. Project Report*.* Sheffield, University of Sheffield. Available from: http://shura.shu.ac.uk/280/1/PDF_Senses_Framework_Report.pdf [Accesed at 14th March 2014]

Nolan, M.R., Davies, S., Brown, J., Keady, J. and Nolan, J. (2002) *Longitudinal Study of the Effectiveness of Educational Preparation to Meet the Needs of Older People and Carers: The AGEIN (Advancing Gerontological Education in Nursing) Project*. London, English National Board for Nursing, Midwifery and Health Visiting. p. 320.

Nolan, M., Ryan, T., Enderby, P. and Reid, D. (2002) Toward a more inclusive vision of dementia care practice and research. *Dementia,* 1(2), 193-211.

Nolan, M.R., Davies, S., Brown, J., Keady, J. and Nolan, J. (2004) Beyond 'person-centred' care: a new vision for gerontological nursing. *International Journal of Older People Nursing in Association with Journal of Clinical Nursing,* 13(3a), 45-53.

Nolan, M., Davies, S., Ryan, T. and Keady, J. (2008) Relationship-centred care and the 'Senses' Framework. *Journal of Dementia Care*, 16(1), 26-8.

Nolan, M.R., Grant, G. and Ellis, N.C. (1990) Stress is in the eye of the beholder: Reconceptualizing the measurement of carer burden. *Journal of Advanced Nursing*, 15(5), 544-55.

Nolan, M., Grant, G. and Keady, J. (1996) *Understanding family care: a multidimensional model of caring and coping*. Buckingham, Open University Press.

Nolan, M., Grant, G., Keady, J. and Lundh, U. (2003) 'New directions for partnerships: relationship-centred care'. In: M, Nolan., U, Lundh., G, Grant. and J, Keady (eds) *Partnerships in family care*. Maidenhead, Open University Press,.

Nolan, M., Keady, J., Grant, G. and Lundh, U. (2003) Introduction: why another book on family care. In: M, Nolan., U, Lundh., G, Grant. and J, Keady (ed) *Partnerships in family care: understanding the caregiving career.* Maidenhead, Open University Press. pp. 1-12.

Nolan, M.R., Keady, J. and Grant, G. (1995) Developing a typology of family care: implications for nurses and other service providers. *Journal of Advanced Nursing*, 21(2), 256-65.

Nolan, M.R., Lundh, U., Grant, G. and Keady, J. (2003) *Partnerships in Family Care: understanding the caregiving career*. Maidenhead, Open University Press,.

Nolan, M.R., Mestheneos, E., Kofahl, C., Johansson, L., Melchiorre, M.G. and Pedich, W. (2008) Issues and challenges in carer support: a consideration of the literature. In: G, Lamura., H, Döhner. and C, Kofahl (eds) Family carers of older people in Europe: A six-country comparative study. London, Transaction Publishers. pp. 17-47.

Norman, I., Redfern, S., Briggs, K. and Askham, J. (2004) Perceptions and management of change by people with dementia and their carers living at home. *Dementia*, 3(1), 19-40.

Nygard, L. (2006) How can we get access to the experiences of people with dementia? *Scandinavian Journal of Occupational Therapy*, 13(2), 101-12.

Orb, A., Eisenhauer, L. and Wynaden, D. (2001) Ethics in qualitative research. *Journal of Nursing Scholarship*, 33(1), 93-6.

Ostwald, S.K., Hepburn, K.W. and Burns, T. (2003) Training family caregivers of patients with dementia: a structures workshop approach. *Journal of Gerontological Nursing,* 29(1), 37-44.

Papastavrou, E., Kalonkerinou, A., Papacostas, S.S., Tsangari, H. and Sourtzi, P. (2007) Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing, 58*(5), 447-57.

Parahoo, K. (1997) *Nursing research. Principles, process, and issues*. London, MacMillan.

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., Leipert, B.D. and Henderson, S.R. (2010) The positive aspects of the caregiving journey with dementia: using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontolology*, 29(5), 640-59.

Peisah, C. (2006) Practical application of family and system theory in old age psychiatry: three case reports. *International Psychogeriatrics,* 18(2), 345-53.

Peisah, C., Brodaty, H. and Quadrio, C. (2006) Family conflict in dementia: prodigal sons and black sheep*. International Journal of Geriatric Psychiatry,* 21(5), 485-92.

Perry, A. (2004) Daughters Giving care to mothers who have dementia: mastering the 3 r’s of (re) calling, (re) learning, (re) adjusting. *Journal of Family Nursing*, 10(1), 50-69.

Petrovitch, H., White, L.R., Ross, G.W., Steinbhorn, S.C., Li, C.Y., Masaki, K.H. Davis, D.G., Nelson, J., Hardman, J., Curb, J.D., Blanchette, P.L., Launer, L.J., Yano, K. and Markesbery, W.R. (2001) Accuracy of clinical criteria for AD in the Honolulu-Asia Aging Study, a population-based study. *Neurology*, 57(2), 226-34.

Phinney, A. (2006) Family strategies for supporting involvement in meaningful activity by persons with dementia. *Journal of Family Nursing,* 12(1), 80-101.

Pimouguet, C., Lavaud, T., Dartigues, J.F. and Helmer, C. (2010) Dementia case management effectiveness on health care costs and resource utilization: a systematic review of randomized controlled trials. *The Journal of Nutrition, Health & Aging,* 14(8), 669-76.

Pinquart, M. and Sörensen, S. (2006) Helping caregivers of persons with dementia: which interventions work and how large are their effects?. *International Psychogeriatrics, 18*(4), 577-95.

Prince, M., Bryce, R. and Ferri, C. (2011) *World Alzheimer Report 2011: the benefits of early diagnosis and intervention.* London, Alzheimer’s Disease International.

Prince, M., Prina, M. and Guerchet, M. (2013) *World Alzheimer Report 2013. Journey of Caring: An analysis of long-term care for dementia.* London, Alzheimer's Disease International.

Puyol, R. and Abellán, A. (2006) Envejecimiento y dependencia. In: R, Puyol. and A, Abellán (ed) *Envejecimiento y dependencia. Una mirada al panorama futuro de la población española.* Madrid, Mondial Assístance. pp. 3-12.

Quinn, C., Clare, L. and Woods, B. (2009) The impact of the quality of relationship on the experience and wellbeing of caring of people with dementia: A systematic literature review. *Aging & Mantal Health,* 13(2), 143-54.

Quinn, C., Clare, L. and Woods, R.T. (2010) The impact of motivations and meanings on the well-being of caregivers of people with dementia: a systematic review. *International Psychogeriatrics*, 22(1), 43-55.

Quinn, C., Clare, L. and Woods, R.T. (2012) What predicts whether caregivers of people with dementia find meaning in their role?. *International Journal of Geriatric Psychiatry,* 27(11), 1195-202.

Rivas, S. (2013) El cuidado y la atención de abuelos dependientes: una oportunidad educative para los nietos. In: A, Muñoz Fernandez (ed) *El cuidado de las personas dependientes ante la crisis del estado de bienestar.* Valencia, Tirant lo Blanch. pp. 253-76.

Roach, P. and Keady, J. (2008) Young people with dementia: time for fair play. Comment piece. *Brithis Journl of Nursing, 17*(11), 690.

Robinson, C.A. (1995) Unifying distinctions for nursing research with persons and families. *Journal of Family Nursing,* 1(1), 8-29.

Rodgers, B.L. and Cowles, K.V. (1993) The qualitative research audit trail: a complex collection of documentation. *Research in Nursing and Health,* 16(3), 219-26.

Rodwell, M.K. (1998) Planning a constructivist study. In: M.K, Rodwell (eds) *Social Work Constructivist Research*. London, Gerland Publishing Inc. pp. 26-48.

Rolland, J.S. (1984) Toward a psychosocial typology of chronic and life-threatening illness. *Family Systems Medicine*, 2(3), 245-63.

Rolland, J.S. (1988) Family systems and chronic illness: a typological model. *Journal of Psychotherapy and the family*, 3(3), 143-68.

Ross, L., Holliman, D. and Dixon, D.R. (2003) Resiliency in family caregivers: implications for social work practice. *Journal of Gerontological Social Work,* 40(3), 81-96.

Sabat, S. (2003) Some potential benefits of creating research partnerships with people with Alzheimer's disease. *Research Policy and Planning*, 21(2), 5-12.

Salvage, A.V. (1995) *Who will care: future prospects for family care of older people in the European Union.* Dublin, European Foundation.

Sanders, S. (2005) Is the glass half empty or half full?. *Social Work in Healt Care,* 40(3), 57-73.

Schulz, R., Belle, S., Czaja, J., McGinnis, A., Stevens, A. and Zhang, S. (2004) Long-term care placement of dementia patients and caregiver health and well-being. *JAMA*, 292(8), 961-7.

Schumacher, L., Stewart, J., Archbold, G., Dodd, J. and Dibble, S.L. (2000) Family caregiving skill: development of the concept. *Research in Nursing and Health*, 23(3), 191-203.

Schwandt, T. (1994) Interpretivist approaches to human inquiry. In: N.K, Denzin (ed) *Handbook of qualitative research*. Thousand Oaks: Sage Publications. pp. 110-32.

Searson, R., Hendrya, A.M., Ramachandranb, R., Burns, A. and Purandare, N. (2008) Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging & Mental Health,* 12(2), 276-82.

Sebern, M. (2005) Shared care, elder and family member skills used to manage burden. *Journal of Advanced Nursing*, 52(2), 170-9.

Seymour, J.E. and Ingleton, C. (1999) Ethical issues in qualitative research at the end of life. *International Journal of Palliative Nursing,* 5(2), 65-73.

Skerrett, K. (2010) Extending Family Nursing: Concepts from positive psychology. *Journal of Family Nursing,* 16(4), 487-502.

Smith, M.J. and Liehr, P.R. (2008) *Middle range theories for nursing*. 2nd edition. New York, Springer.

Smith, M.J. and Liehr, P.R. (2008) Understanding middle range theory by moving up and down the ladder of abstraction. In: M.J, Smith. and P.R, Liehr. 2nd edition. *Middle range theory for nursing.* New York, Springer Publishing Company, LLC. pp. 13-33.

Snyder, L. (2001) Understanding the feelings and subjective accounts of persons with the disease. *Alzheimer's Care Quarterly,* 2(2), 8-22.

Spanish Statistical Office (2013) *Short-Term Population Projection for Spain, 2013-2023.* [online]. Madrid, INE Press. Available from: http://www.ine.es/en/prensa/np813_en.pdf [Accessed at 14th March 2014].

Spanish Statistical Office (2013) *Notas de Prensa. Cifras de Población a 1 de julio de 2013 Estadística de Migraciones. Primer semestre de 2013*. [online]. Available from: http://www.ine.es/prensa/np822.pdf [Accessed at 14th March 2014].

St. John, W., and Rolls, C. (1996) Teaching family nursing: strategies and experiences. *Journal of Advanced Nursing*, 23 (1), 91-96.

Steeman, E., De Casterlé, B.D., Godderis, J. and Grypdonck, M. (2006) Living with early-stage dementia: a review of qualitative studies. *Journal of Advanced Nursing,* 54(6), 722-38.

Steenvoorden, M., van der Pas, F. and de Boer, N. (1993) Family care of the older elderly: casebook of initiatives. Dublin, European Foundation.

Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research: Grounded Theory, Procedures and Techniques.* Newbury Park, Sage Publications.

Streubert, H. and Carpenter, D.R. (1995) *Qualitative research in nursing. Advancing the humanistic imperative.* Philadelphia, Lippincott Company.

Taylor, S.J. and Bogdan, R. (1984) *Introduction to qualitative research methods: the search for meanings.* 2nd edition. New York, John Wiley & Sons.

Taylor, S.J. and Bogdan, R. (1998) *Introduction to qualitative research method.* 3rd edition. New York, John Wiley & Sons, Inc.

Thomas, D.R. (2006) A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*, 27(2), 237-46.

Thomas, H. (2010) Attitudes of primary care team to diagnosing dementia. *Nursing Older People*, 22(3), 23-7.

Thornberg, R. (2012) Informed Grounded Theory. *Scandinavian Journal of Educational Research,* 56(3), 243-59.

Topping, A. (2008) El espectro continuo cuantitativo-cualitativo. In: K, Gerrish. and A, Lacey (ed) *Investigación en enfermería*. Madrid, McGraw Hill. pp. 157-72.

Turner, L. and West, R. (2002) *Perspectives on Family Communication*. Boston, McGraw Hill.

Turner, S., Iliffe, S., Downs, M., Wilcock, J., Bryans, M., Levin, E., Keady, J. and O'Carroll, R. (2004) 'General Practioner's knowledge, confidence and attitudes in the diagnosis and management of dementia'. *Age & Ageing,* 33(5), 461-67.

UK Parliament (1998) *Data protection act*. [online]. London, Her Majesty's Stationery Office (HMSO). Available from: http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_1 [Accessed at 10th September 2011].

United Nations, Department of Economic and Social Affair (2007*) World Economic and Social Survey 2007: Development in an Ageing World.* [online]. New York*,* United Nations. Available from: http://www.un.org/en/development/desa/policy/wess/wess_archive/2007wess.pdf [Accessed at 10th September 2011].

United Nations, Department of Economic and Social Affair (2012) *Population ageing and development.* [online]. New York, United Nations. Available from: http://www.un.org/esa/population/publications/2012WorldPopAgeingDev_Chart/2012PopAgeingandDev_WallChart.pdf [Accessed at 14th March 2014].

Urquhart, C. (2007) The evolving nature of grounded theory method: The case of the information systems discipline. In: A, Bryant. and K, Charmaz (ed) *The SAGE handbook of grounded theory.* Los Angeles, Sage. pp. 339-60.

Van Manen, M. (2002) Care-as-Worry, or Don`t Worry, Be Happy. *Qualitative Health Research*, 12(2), 262-78.

Varma, A.R., Snowden, J.S., Lloyd, J.J., Talbot, P.R., Mann, D.M. and Neary, D. (1999) Evaluation of the NINCDS-ADRDA criteria in the differentiation of Alzheimer's disease and frontotemporal dementia. *Journal of Neurology Neurosurgery and Psychiatry*, 66(2), 184-8.

Vellone, E., Piras, G., Talucci, C. and Zichi, M. (2008) Quality of life for caregivers of people with Alzheimer's disease*. Journal of Advanced Nursing,* 61(2), 222-31.

Verbrugge, L. and Jette, A. (1994) The disablement process. *Social Science & Medicine,* 38(1),1-14.

Virani, T., Lemieux-Charles, L., Davis, D.A. and Berta, W. (2009) Sustaining change: Once evidenced-based practices are transferred, what then?. *Health Care Quarterly*, 12(1), 89-96.

Vivar, C.G., Arantzamendi, M., López-Dicastillo, O. and Gordo, C. (2010) La teoría fundamentada como metodología de investigación cualitativa. *Index de Enfermería*, 19(4), 283-8.

Walker, D. and Myrick, F. (2006) Grounded theory: an exploration of process and procedure. *Qualitative Health Research*, 16(4), 547-59.

Wancata, J., Musalek, M., Alexandrowicz, R. and Krautgartner, M. (2003) Number of dementia sufferers in Europe between the years 2000 and 2050. *European Psychiatry,* 18(6), 306-13

Ward-Griffin, C. and Mckeever, P. (2000) Relationships between nurses and family caregivers: partners in care. *Advances in Nursing Science*, 22(3), 89-103.

Weaks, D. and Boardman, G. (2003) Normalization as a philosophy of dementia care. In: J, Keady., C.C, Clarke. and T, Adams (ed) *Community mental health nursing and dementia care.* Philadelphia, Open University Press. pp. 186-98.

Welsh, E. (2002) *Dealing with data: using NVivo in the Qualitative Data Analysis Process.* [online]. *Qualitative Social Research Forum*, 3(2). Available from: http://www.qualitative-research.net/index.php/fqs/article/view/865/1880

Weyl, M. (2009) Love song at the end of the day: A wife´s journey. *Dementia,* 8(1), 9-15.

Wilkinson, H. (2002) Including people with dementia in research: Methods and motivations. In H. Wilkinson (ed), *The perspectives of people with dementia: research methods and motivations*. London, Jessica Kingsley. pp. 9–24.

Wilkinson, M. and Lynn, J. (2005) Caregiving for advanced chronic illness patients. *Techniques in Regional Anesthesia and Pain Management*, 9(3), 122-32.

Wilson, H.S. (1989) Family caregivers: the experience of Alzheimer's disease. *Applied Nursing Research,* 2(1), 40-5.

Willoughby, J. and Keating, N. (1991) Being In Control: The Process of Caring for a Relative with Alzheimer's Disease. *Qualitative Health Research,* 1(1), 27-50.

Woods, R.T. (2001) Discovering the person with Alzheimer’s disease: Cognitive, emotional and behavioural aspects. *Aging and Mental Health,* 5, S7-16.

World Health Organization (1993) *The ICD-10 classification of mental and behavioural disorders:Clinical descriptions and diagnostic guidelines.* Geneva, WHO Press. Available from: http://www.who.int/classifications/icd/en/bluebook.pdf [Accesed at 21st February 2011].

World Health Organization (2001) *The world health report 2001, Mental health: New understanding, new hope*. [online]. Geneva, WHO Press. Available from: http://www.who.int/whr/2001/en/whr01_en.pdf?ua=1 [Accesed at 21st February 2011].

World Health Organization (2005) *Preventing chronic diseases: a vital investment, WHO global report.* [online]. Geneva, WHO Press. Available from: http://whqlibdoc.who.int/publications/2005/9241563001_eng.pdf [Accesed at 21st February 2011].

World Health Organization (2006) *Working together for health*. [online]. Geneva, WHO Press. Available from: http://www.who.int/whr/2006/whr06_en.pdf?ua=1 [Accesed at 21st February 2011].

World Health Organization (2012) *Dementia: a public health priority.* [online]. Geneva, WHO Press. Available from: http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf [Accessed at 14th March 2014].

World Health Organization (2013) *World health statistics.* [online]. Geneva, WHO Press. Available from: http://konyvtar.eski.hu/tmpimg/1237387712_0.pdf [Accessed at 14th March 2014].

Wright, L. M., and Bell, J. M. (2009) *Beliefs and illness: A model for healing.* 4th edition. Calgary, Canada, Floor Press.

Wright, L.M., and Leahey, J.M. (2000) *Nurses and families: A guide to family assessment and intervention*. 3rd edition. Philadelphia, F.A. Davis.

Wright, L.M. and Leahey, J.M. (2009) *Nurses and families: A guide to family assessment and intervention*. 5th edition. Philadelphia, F.A. Davis.

Yamashita, M. and Amagai, M. (2008) Family caregiving in dementia in Japan. *Applied Nursing Research,* 21(4), 227-31.

Zugasti, M.J. (2013) *Salud, discapacidad y dependencia: relaciones entre el sistema sanitario y el de servicios sociales*. In: A, Muñoz Fernández (ed) El cuidado de las personas dependientes ante la crisis del estado de bienestar. Valencia, Tirant lo Blanch. pp. 347-66.

APPENDICES

APPENDICES CHAPTER 4

Appendix 4.1 Information Sheet for the Memory Unit and Health Professionals

Pamplona, January 2012

FAMILY EXPERIENCES OF LIVING WITH ALZHEIMER'S DISEASE: A GROUNDED THEORY STUDY

I. Introduction

The following document provides a brief description of the study *'Family experiences of living with Alzheimer's disease: a grounded theory study'* aimed at exploring the family experience of living with early stage Alzheimer´s Disease (AD) through the shared experiences of the family members and the person with AD.

The study is conducted by Nuria Esandi, nursing researcher and teaching assistance at the University of Navarra, and supported by Prof. Dr. Mike Nolan (University of Sheffield, UK) and Dr.Ana Canga (University of Navarra).

The principal objectives of the study are:

- **a.** Exploring how the experience of AD affects the structure and dynamics of the family unit (family relationships, interactions, roles…).
- **b.** Understanding what living with AD means to the person and the others involved
- **c.** Identifying the main needs, concerns and demands of the family (including those of the person with AD) as well as the resources and strengths that families have.
- **d.** Finally, the study seeks to explain the family process that takes place in living with AD, considering how this knowledge may help to improve care and development of support services targeted to the whole family unit including the person with AD (special attention is given to the nursing role).

II. Justification and relevance of the study

The progressive increase of incidence and prevalence rates of Alzheimer's disease as well as its impact on the person and families place this condition as a key priority in social and health policy agendas. Thus the promotion of best practices focused on early diagnosis and family support is receiving increasing attention (European Commission, 2009).

AD is still a chronic and incurable disease which leads the person to a progressive situation of dependence. However its impact is not limited to the loss of personal autonomy but extends to people, often family members, that support and care for the person (Andren and Elmstahl 2008, Ferrara et al., 2008). AD and the new situation created as a result may alter the structure and the 'normal' functioning of the family. Changes in communication patterns, the relationships between different members of the family and family roles may pose potential conflicts that could compromise the way the family perceives and accepts the new situation.

Although the family is still the main source of support and care for these people, and it cannot longer sustain the care alone (Puyol and Abellan, 2006). AD is not just a family matter but an issue that affects society as a whole and requires commitments and responsibilities of both the family and the state, in addressing issues related to the protection, support and funding (Ministry of Labour and Social Affairs, 2006). Addressing family needs and demands requires new social policies that focus on supporting and working with families to improve and maintain the quality of life of both the person affected and the family (Wood, 2001; Quinn et al., 2009). Therefore, AD care requires an holistic, interdisciplinary, multidisciplinary and integrated (health and social services) approach aimed at: -offering support and care to the person with AD and their families, -protecting the interests of both parties, -recognizing the value and the identity of the person with AD over the course of the disease and -preserving the ordinary aspects of life (Weaks and Boardman, 2003). Accordingly people with AD and their families have the total right to access care services that allow them to continue living their life as better as possible.

So far the vast majority of research in family care and dementia field has focused primarily on dyadic affective relationships (person with AD and the main caregiver), the burdens of care and the caregiver stress, and rarely have adopted a family system approach, underestimating the need to work in this direction. Moreover, despite growing attention to the positive aspects of care in the AD, the negative perspective of this situation still prevails in professional and research field. There is a significant gap in the comprehension and understanding of how the family as a whole live with AD, the role all its members adopt, the effect this condition has on them as well as what are the main objectives strengths, needs and concerns they identify as a family.

Understanding the family experience of AD, from the life experiences of its protagonists may be an important resource in the development of professional care services close to family realities, in which professional evaluation and interventions are directed not only to the person with AD but to the family, as whole, and its context. Somehow the findings of this study may establish a good opportunity for the advancement and improvement of interventions that also take into account the family strengths and resources, and thus satisfy their real demand adequately.

III. Practical issues of the study

The study is focused on families currently living with early stage of AD. Participants will be selected according to the following criteria:

People with AD

- People aged 65 and over and living at home. Individuals will be of both genders, as their role in the family may differ and AD may perhaps cause a different impact on the family dynamics.
- Only people with a diagnosis of suspected Alzheimer´s disease established by clinical examination, the Mini-Mental State Examination (MMSE), and confirmed by neuropsychological tests will be included. Judgments about their suitability for the study will be base on the person´s adjustment and willingness to talk about their ‘memory loss’; the level of competence and ability to understand and give informed consent; and retained verbal fluency and level of concentration.
- The person with AD will be at an early-mild stage of the disease, which will allow exploring the early impact on the family and ensuring that the person will play an active role in the interviews.

Relatives

- Family support will be carried out at home.

- It is not necessary that each family member live with the person but they must live close enough to assume a share of care activities or be deemed by the person with AD to provide them with important sources of support.

Participation is completely voluntary, so that participants have the right to leave the study at their convenience. In addition, the principal researcher will inform verbally of the study and provide an information sheet and informed consent so that potential participants understand correctly the purpose of the study and can make an informed decision to get involve. Once the researcher obtains the informed consent participants will be interviewed in order to know their personal experience about the phenomenon.

Interviews will be both individual and collective. During the interviews people will be invited to share their experience through open questions about their personal experience with AD and the consequences to the family. If participants allow, the interviews will be fully recorded in order to facilitate further analysis of data.

In this study absolute confidentiality and anonymity of participants is guaranteed. Data from the study will be protected throughout the process and will be used exclusively for the purpose for which it was designed. Furthermore, the study results will be available to participants for review. Information gathered during the interviews will be completely confidential and not shared with anyone, including members of the same family (in case of individual interviews)

Contact address
Nuria Esandi Larramendi
University of Navarra
Faculty of Nursing
Adult Health Nursing Department
nelarramend@unav.es
Ph. 669260621/ 948 425645 Ext. 6611

Appendix 4.2 Information Sheet for the Relatives

Adult Health Nursing Department
Faculty of Nursing, University of Navarra
1 Irunlarrea St.
31001, Pamplona

Introduction: The following document contains information about a study conducted by the Faculty of Nursing, at the University of Navarra, aimed at exploring the experiences of people who are experiencing early 'memory loss' episodes and those of their relatives.

The study aims to:

1. Comprehend the experience of the whole family in living with 'memory loss'
2. Understand the meaning and implications it has for the family unit.
3. Identify the needs, concerns and demands of the family at that time.
4. Recognize the resources and strengths families have living with this situation.

Requirements: The study focuses on the whole family experience so it is open to all family members who wish to take part on it, as long as the following criteria are met:

- You: It is not necessary that you live in the same house your relative suffering from 'memory loss' does. However you must assume a share of care activities or provide him/her with important sources of support.
- Your relative is required to age 65 or over, being male or female. It is important he/she is able to actively participate in our conversations since it will allow us getting his/her personal experience.

Contribution: It is the intent of this study to contribute to knowledge on the family experience of living with 'memory loss' and the development of future care plans aimed at the wellbeing of the entire family.

Your participation in this study will be voluntary so you could leave it at any time you wish. An informed consent (verbal and written) will be required declaring you were informed about the study, comprehended and understood its purpose and agreed to participate.

Interviews: A series of interviews will be undertaken with you and your family, individual or jointly according to your preferences. During the encounters you all will be invited to share your experiences with ‘memory loss’ and its implications. You may refuse to address any issues you might not want to share. Our conversations will be audio recorded, if allowed, in order to facilitate further analysis of data. However once the study is completed all the recordings will be destroyed.

Conversation would last about 40-60 minutes. It is expected to complete three family encounters approximately over a year with the aim of clarifying and expanding knowledge and information.

Absolute **confidentiality and anonymity** will be guaranteed throughout the study. Data will be protected and used exclusively for the study purposes. The information shared during our conversations will be completely private and confidential. Your anonymity will be preserved throughout the study and especially in the process of the result´s dissemination.

For any questions or comments, please do not hesitate to contact me, **Nuria Esandi**, either by phone at **948-425600/ 669260621** or by email at the following address **nelarramend@unav.es**

Let me thank you in advance for considering this document. I will appreciate your reflection on taking part in the study since your collaboration could be very useful.

Yours sincerely

Nuria Esandi

Appendix 4.3 Information Sheet for the Person

Adult Health Nursing Department
Faculty of Nursing, University of Navarra
1 Irunlarrea St.
31001, Pamplona

Introduction: The following document contains information about a study conducted by the Faculty of Nursing, at the University of Navarra, aimed at exploring the experiences of people who are experiencing early 'memory loss' episodes and those of their relatives.

The study aims to:

1. Comprehend the experience of your family regarding 'memory loss'
2. Understand the meaning and implications that those 'memory loss' episodes has for you and your relatives
3. Identify your needs and concerns and those of your family
4. Recognize the resources and strengths you and your family has.

Requirements: The study focuses on the whole family experience so it is open to all family members who wish to take part on it, as long as the following criteria are met:

- You will be aged 65 or over, male or female, willing to share your experience and actively participate in our conversations.
- You relatives: They must live close enough to share the experience with you or provide you with important sources of support.

Your participation in this study will be voluntary so you could leave it at any time you wish. An informed consent (verbal and written) will be required declaring you were informed about the study, comprehended and understood its purpose and agreed to participate.

Interviews: A series of interviews will be undertaken with you and your relatives, individual or jointly according to your preferences. During the encounters you will be invited to share your experiences with ‘memory loss’ episodes. You may refuse to address any issues you might not want to share. Our conversations will be audio recorded, if allowed, in order to facilitate further analysis of data. However once the study is completed all the recordings will be destroyed.

Conversation would last about 40-60 minutes. It is expected to complete three family encounters approximately with the aim of clarifying and expanding knowledge and information.

Absolute **confidentiality and anonymity** will be guaranteed throughout the study. The information shared during our conversations will be completely private and confidential. Your anonymity will be preserved throughout the study.

For any questions or comments, please do not hesitate to contact me, **Nuria Esandi**, either by phone at **948-425600/ 669260621** or by email at the following address **nelarramend@unav.es**

Let me thank you in advance for considering this document. I will appreciate your reflection on taking part in the study since your collaboration could be very useful.

Yours sincerely

Nuria Esandi

Appendix 4.4 Consent Form of the Relatives

I, ……………………………………, declare I was informed by Nuria Esandi Larramendi about the study aimed at exploring the experiences of people who are experiencing early ‘memory loss’ episodes and those of their relatives.

The interview:

I understand that taking part in the study involves being interviewed individual and/ or jointly with other members of my family who also agreed to participate. In both cases the researcher ensures absolute confidentiality by not disclosing personal information to anyone, including my relatives. The place and date of the interviews will be settled in advance according to my preferences and those of my family. Likewise Nuria Esandi explained me that the interviews will be audio recorded if I previously allow it. However once the study concludes the recordings will be destroyed.

I have the right to refuse to answer any questions I do not want to share and the freedom to withdraw the study at any time. I confirm that I received enough information about data confidentiality and anonymity.

Therefore I declare that:

- ☐ I agree to take part in the study and this research interview to be taped-recorded.
- ☐ I agree to take part in the study but <u>DO NOT</u> agree this research interview to be taped-recorded.

....

(Participant name and signature)

....

(Researcher name and signature)

....

Date

Appendix 4.5 Consent Form of the Person

I, ……………………………………, declare I was informed by Nuria Esandi Larramendi about the study aimed at exploring the experiences of people who are experiencing early ‘memory loss’ episodes and those of their relatives.

The interview:

I understand that taking part in the study involves being interviewed individual and/ or jointly with other members of my family who also agreed to participate. In both cases the researcher ensures absolute confidentiality by not disclosing personal information to anyone, including my relatives. The place and date of the interviews will be settled in advance according to my preferences and those of my family. Likewise Nuria Esandi explained me that the interviews will be audio recorded if I previously allow it. However once the study concludes the recordings will be destroyed.

I have the right to refuse to answer any questions I do not want to share and the freedom to withdraw the study at any time. I confirm that I received enough information about data confidentiality and anonymity.

Therefore I declare that:

- ☐ I agree to take part in the study and this research interview to be taped-recorded.
- ☐ I agree to take part in the study but <u>DO NOT</u> agree this research interview to be taped-recorded.

....

(Participant name and signature)

....

(Researcher name and signature)

....

Date

Appendix 4.6 Initial Interview Schedule

Introduction + clarification of the study purpose and the content of the interview

Thematic area: onset of ‘memory loss’ and impact on family life

- To start, Could you tell me about when you/your relatives’ ‘memory loss’ episodes started and how did you notice them?
- How you felt at that time? And now?
- What do you think about these episodes?
- Could you tell me if there have been any changed in your life since then? (routines)
- Has your (family) life changed from before and after the memory loss episodes?
- How are you involved in this situation (family life changes)?
- Could you tell me a bit about your relationship and contact within your family?
- Do you think it (memory loss) has changed your family relationships?

Thematic area: family needs and concerns/ family resources

- Do you think that this situation (memory loss) may affect your future expectations? In what way?
- Is there something that you are concerned about?
- What are the main challenges you all are facing?
- What do you think are the most important ways to cope with ‘memory loss’?
- Have you received any help, support or guidance? From who/ where? How has he/she helpful?
- Is there anything that you might not have thought about before that has occurred to you during this interview?

- Would you like to highlight or add something that you think I should know or understand better? (I will clarify data or information that has not been clear, and confirm the main points provided by the interviewee).
- Is there anything you would like to ask me?

*Note: The person with AD and the family members will be asked about the same topics, however the question's format may vary in some cases (direct questions or questions about a third party)

Appendix 4.7 Demographic-data sheet

Gender: ☐ Female ☐ Male

Marital status: ☐ Married ☐ Single ☐ Widow

N° Children…………………

Age: ………………………………………

Education: ………………………………..

Employment: …………………………..

☐ Full time ☐ Part time ☐ Housewife

☐ Senior citizen ☐ Unemployed ☐ Low labor

Residence/accommodation: ……………………………………

☐ City ☐ Rural area

☐ Alone ☐ With someone ☐ Daily family visit

Diagnosis (stage): ……………… **Family history (health status)**……………..

MMSE: ……………………………….

***GERC:** ……………………………….

Length of time in the Memory Unit: ………………………………………..

Months after diagnosis:

☐ Less than 1 month ☐ 1 month ☐ 2 months ☐ 3 months

☐ 4 months ☐ 5 months ☐ 6 months ☐ > 6 months

RELATIVE 1

Gender: ☐ Female ☐ Male

Marital status: ☐ Married ☐ Single

N° Children..................................

Age: ....

Education: ....

Employment: ....

☐ Full time ☐ Part time ☐ Housewife

☐ Senior citizen ☐ Unemployed ☐ Low labor

Residence/accommodation: ....

☐ City ☐ Rural area

☐ Alone ☐ With someone ☐ Daily family visit

Relative: ....

☐ Wife/husband ☐ Son/daughter ☐ Sister/brother

☐ Son/daughter in-law ☐ Other ....

RELATIVE 2

Gender: ☐ Female ☐ Male

Marital status: ☐ Married ☐ Single

N° Children.......................................

Age: ....

Education: ....

Employment: ....

☐ Full time ☐ Part time ☐ Housewife

☐ Senior citizen ☐ Unemployed ☐ Low labor

Residence/accommodation: ....

☐ City ☐ Rural area

☐ Alone ☐ With someone ☐ Daily family visit

Relative: ....

☐ Wife/husband ☐ Son/daughter ☐ Sister/brother

☐ Son/daughter in-law ☐ Other..................................

RELATIVE 3

Gender: ☐ Female ☐ Male

Marital status: ☐ Married ☐ Single

N° Children......................................

Age: ....

Education: ....

Employment: ....

☐ Full time ☐ Part time ☐ Housewife

☐ Senior citizen ☐ Unemployed ☐ Low labor

Residence/accommodation: ....

☐ City ☐ Rural area

☐ Alone ☐ With someone ☐ aily family visit

Relative: ....

☐ Wife/husband ☐ Son/daughter ☐ Sister/brother

☐ Son/daughter in-law ☐ Other ....

ADDITIONAL NOTES OF THE FAMILY UNIT, IF REQUIRED

....

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***GERMICIDE:** Protocol for basic neuropsychological assessment. Spanish Society of Neurology.

Appendix 4.8 Interviews Calendar

	Armendariz	Blasco	Cervera	Dominguez	Estevez	Gonzalez	Jimenez
Introductory Meeting **Telephone and email contact**	Date: 08/03/2012 Place: Memory Unit FMemeber. Abel, Anne, Adela	Date: 16/03/2012 Place: Memory Unit FMember: Bea, Blanca	Date: 09/03/2012 Place: Memory Unit FMember: Carmen, Carlos, Cecilia, Camila	Date: 28/02/2013 Phone contact FMember: David	Date: 28/02/2013 Phone contact FMember: Elisa	Date: 28/02/2013 Phone contact FMember: Gemma	Date: 28/02/2013 Phone contact FMember: Justina
1st Interview	(1) Date: 22/03/2012 Place: Couple's House FMember: Abel, Anne, Adela	(2) Date: 23/03/2012 Place: Bea's House FMember: Bea, Beatriz, Blanca (3) Date: 04/04/2012 Place: Memory Unit FMember: Barbara	(4) Date: 26/05/2012 Place: Couple's House (in the city) FMember: Carmen, Carlos, Cecilia, Camila	(6) Date: 04/04/2013 Place: Daniela's House FMember: Daniela, David, Denia,	(17) Date: 05/11/2013 Place: The University of Navarra FMember: Elisa	(7) Date: 29/04/2013 Place: Gabriel's House FMember: Gabriel, Gemma	(8) Date: 27/05/2013 Place: Memory Unit FMember: Justina, Jimena, Julieta
2nd Interview	(5) Date: 25/06/2012 Place: Couple's House FMember: Anne	(9) Date: 14/08/2013 Place: Bea's House FMember: Barbara (10) Date: 14/08/2013 Place: Bea's House FMember: Bea, Blanca	(11) Date: 26/09/2013 Place: Carla's House FMember: Cecilia, Carla	(12) Date: 12/08/2013 Place: David's House FMember: David	(19) Date: 26/11/2013 Place: Elena's House FMember: Elena (+Elisa)	(13) Date: 24/09/2013 Place: Gemma's House FMember: Gemma	(18) Date: 21/11/2013 Place: Memory Unit FMember: Jimena, Julieta
3th Interview	Date: 21/03/2013 FMemeber: Anne	(26) Date: 05/03/2014	(15) Date: 25/10/2013	(14) Date: 02/10/2013	(22) Date: 25/02/ 2014	(16) Date: 30/10/2013	(20) Date: 31/01/2014

	*Phone contact Anne expressed her and her family willingness to be interviewed again. However she stated that month would be the best moment. Few months later I contacted her again. I perceived she was more restless and worried about Abel’s situation... We chat a little bit and he explained she had noticed her husband’s situation got worst and she would not want to talk about but just care about him. However expressed her desire to be in contact and hear about the study finding at some point in time.	Place: Bea’s House FMember: Bea, Blanca	Place: Carla’s House FMember: Carmen (16) Date: 25/10/2013 Place: Carla’s House FM: Carmen, Carla	Place: Daniela’s House FMember: Daniela	Place: The University of Navarra FMember: Elisa	FMember: Gabriel *Phone contact Gabriela, the daughter, called me few minutes before the encounter to tell me that her father did not want to see nobody and it could be better to change the date of the interview. Unfortunately It could not be possible to arrange another encounter with him.	Place: Memory Unit FMember: Justina
4th interview			(21) Date: 21/02/2014 Place: Carla’s House FMember: Cecilia, Carla	(23) Date: 25/02/2014 Place: Daniela’s House FMember: David (+ Daniela)		(24) Date: 27/02/2014 Place: Gemma’s House FMember: Gemma	(25) Date: 27/02/2014 Place: Memory Unit FMember: Jimena, Julieta

Appendix 4.9 Example of Initial codification

Date/ Time: 25/06/2012; **Venue:** Family House
Family: The Armendariz **Interviewer:** Nuria **Interviewee:** Anne (Wife)
Nº of interview: 2nd

CONTENT	CODE
Nuria: Anne, could you tell me a little about how you feel about this new situation?	
Anne: look Nuria, This has affected me a lot.	'Affecting me a lot'
Nuria: This has affected you… could you expand a little bit on this?	
Anne: This affects everything. In the past he was very, very dynamic. He has always been working away from home, working in the lab. He had lot of contact with people and staff. I noticed he is a little bit sad.	'Affecting everything' Comparing with the past Describing his husband personality (Being very active) Noticing him sad (now)
Nuria: Anne, how you see your husband is at present?	
Anne: I feel as if he would not longer have 'that thing' he had before. I've also noticed he is a little absent. I observe him… I've notice that… I will tell it to the doctor the day we go there. I've notice that his hands temble a little bit. Perhaps this is due to the medication he takes. He is tanking it for long time so I don't know if this may cause harm to him.., or this is a consequence of the condition.	Comparing with the past Noticing him absent Observing him New symptom reported to Dr. Noticing hands tembling Expressing uncertainty about the cause
Nuria: (nods)	
Anne: I always telling him, 'Abel please made some exercises!' But I see he has his hand a little bit atrophied.	Encouraging to make exercises Noticing difficulties in his hands
Nuria: (nods)	
Anne: He has not this desire for doing things. I try to encourage him, and this is how we're doing. Many times, I understand that…, I put	Losing initiative Encouraging him to do things

myself the objective of being patient. But sometimes I think that I fly off the handle, you know?	Trying to be patient (purpose) Breaking purposes (being patient)
Nuria: I know what you mean	
Anne: Hi Abel! Here I am with Nuria; you do not know who is, do you?	
Nuria: How are you Abel?	
Abel: I´m fine. I am sorry ladies but I am leaving.	
Nuria: Yeah, of course.	
Anne: (Whispering) Do not worry, Once he left home, we will chat a little bit.	Hiding attitude
Nuria: As you prefer Anne.	
Anne: Yes, yes. Because I do not want that he… As I was telling you, I try to be patient. For instance I say to him something I have to repeat it again and then I say to him: ‘I´ve already told you that’. I try to be patient but… I told this to the GP because she noticed that I was a bit nervous. I am not sleeping very well so she recommended me to take some pills… That’s what I’ve told you that I am not dealing very well with it. I am not doing as good as I would like to do it but… (Abel came into the room). Sorry but I prefer he leaves because otherwise he…	Hiding attitude Trying to be patient Repeating things to him Breaking off the purpose Receiving medical attention Not sleeping very well Not dealing very well Demanding herself Hiding attitude
Nuria: As you both prefer.	
Anne: Now we are going to travel, we are going to (place). Once he concludes with the memory unit programme we will go to (place), thus he will get relax, he will see his relatives…	Making new plans Doing things that pleased
Nuria: Fresh air!	
Anne: Yeah, I think we need a change. However I do not feel as comfortable as I was before when we travelled together. He might have some distractions while driving so… but	Needing a change Feeling uncomfortable-unsecure Fearing he has driving

we take care.	distractions
[Anne talked to Abel before he leaves home]	
Nuria: By Abel, Take care yourself!	
Anne: By Abel. And this how we're doing Nuria. Everything I can do it for him I will do it. This way he does not see himself so…	Doing as possible Supporting him above all
Nuria: Anne, what happen when Abel noticed that something happened to him?	
Anne: He said 'don't say stupid things' He also answered with 'well well, well …' But he noticed and he still notices it.	Hiding Noticing his own difficulties
Nuria: Did he try to hide these?	
Anne: Yeah, yeah. He started saying 'well, well...'	Hiding
Nuria: I know, I know.	
Anne: Look, this happened yesterday. Yesterday it was 'San Juan'. His father called 'Juan' and his brother too. Then I said, 'let's see if he remembered that'. But he did not do it. Today he remembered it and he said: I did not call my brother… and I said to him: 'How did you forget it?' And he told me: 'I do not, I forgot it and that's it'. He forgot it. He forgets many things but… What can we do? (She start crying)	Assesing Downplaying the forgetfulness What can we do?
Nuria: Don´t worry Anne. (I hold her hand)	
Anne: I have to accept it, but this hurts me a lot. Down this floor, I think is in the 6th floor, there is a men living… I think he is in his sixties, and he is… This is a complete shame! Oh my God! How bad this disease is! Thanks God that I have two children that care about us a lot	Displaying suffering Feeling shame Negative dimension of AD Receiving (children) support
Nuria: You mentioned that during one first encounter. You said you feel really supported by them…	
Anne: Of course. Look, Adrian that lives in	

USA, he calls home every day: ‘How is dad	Close caring
today?’ Everything we need they are really	Willing to support
willing to help with. But this is something that	Having no solution
does not have solution. This is a shame. Now,	Feeling shame
that our children are adults, that we have very	
nice grandchildren… This is a little bit sad but…	Feeling sadness
this is life.	
Nuria: Before, you mentioned that you feel	
nervous, don’t you?	
Anne: Yeah, I wake up every day in the middle	Waking up at night
of the night… But look, few weeks ago I hear	
that in the church there would take place the	Seeking relief
sacrament of anointing of the sick and we both	Receiving the extreme unction
attended it. And the day I had the appointment	
with the GP and she told me: ‘Anne, you had to	Receiving health care support
be prepared, because this is life’ I replied to	
her: ‘I am prepared. Look how prepared we are	
that we have already received the extreme	Feeling relief
unction. I asked Abel: ‘Do you want to go	Religion as a support
honey?’ And he told me: ‘If you want…’ Before	Agreeing
this sacrament was for dying people, but now	Changing beliefs
we’ve received it being healthy.	
[The phone rang and the interviewed was	
interrupted. Anne talked to Adrian, her son.]	
Anne: What am I saying? Oh yes, that this	Feeling sad
situation is a bit sad. Now that we are getting	
older the problems arise. But life is about it.	Finding difficulties in life
First of all, taking care of the children. And later,	Caring for children as a purpose
when you think that your children are adults,	Identifying life expectation
they have a position and they are alright, this	Broken life expectation
come to us. But, what should I say? Of course	
this has affected me. Because before we did	Confining mi life
many things.	Comparing with the past
Nuria: Do you feel you life has changed?	
Anne: Of course! Before we do lot of things, we	Comparing with the past

travel… Now, I go to the memory unit with him… I do not know. Everything has changed, of course.	‘Everything has change’
Nuria: What about your relationship Anne?	
Anne: Everything. Everything is changing.	‘Everything is changing’
Nuria: Everything	
Anne: Everything. Sometimes I wake up with good purposes but… But I am always keeping an eye on what he is doing. For example I like that he close the door before going to sleep, thus he realizes… thus he had things to do...	Keeping an eye on Giving him the responsibility of closing the door
Nuria: You mean responsibilities?	
Anne: Exactly. Because I`ve noticed that he lacks of initiative to do it by himself.	Noticing lack of initiative
Yesterday Adela told me: ‘Mom, dad is not longer… you should take on the house finances’ He has always managed the money. He has always managed our business. I have not cared about nothing. But my daughter told me that I should start taking on that responsibility. But look, I think that if I start doing this he is going to feel a little bit… what you think Nuria?	Children as guardians Taking on the management of finances Identifying family responsibilities Taking on new responsibility Avoiding to cause harm to him
Nuria: Anne, let me see if I understand your point, but you do not want to take his responsibilities off, do you? Because Abel might feel bad.	
Anne: Exactly Nuria. Look, when we go shopping I always say to him: ‘you have to pay Abel’, and I observe what he does. He use credit card as well… but at less this way he…you know?	Letting him pay in the shops Observing Avoiding to cause harm to him

Appendix 4.10 Example of Focused Coding

Date/ Time: 25/06/2012**; Venue:** Family house

Family: The Armendariz **Interviewer:** Nuria **Interviewee:** Anne (Wife)

Nº of interview: 2nd

CONTENT	CODE
Nuria: Anne, could you tell me a little about how you feel about this new situation?	
Anne: look Nuria, This has affected me a lot.	
Nuria: This has affected you… could you expand a little bit on this?	
Anne: This affects everything. In the past he was very, very dynamic. He has always been working away from home, working in the lab. He had lot of contact with people and staff. I noticed he is a little bit sad.	Everything is changing Noticing the loss
Nuria: Anne, how you see your husband is at present?	
Anne: I feel as if he would not longer have 'that thing' he had before. I've also noticed he is a little absent. I observe him… I've notice that… I will tell it to the doctor the day we go there. I've noticed that his hands temble a little bit. Perhaps this is due to the medication he takes. He is tanking it for long time so I don't know if this may cause harm to him.., or this is a consequence of the condition.	Noticing the loss
Nuria: (nods)	
Anne: I always tell him, 'Abel please made some exercises!' But I see he has his hand a little bit atrophied.	Caring for Noticing the loss
Nuria: (nods)	
Anne: He has not this desire for doing things. I try to encourage him, and this is how we're	Noticing the loss

doing. Many times, I understand that…, I put myself the objective of being patient. But sometimes I think that I fly off the handle, you know?	
Nuria: I know what you mean	
Anne: Hi Abel! Here I am with Nuria; you do not know who is, do you?	
Nuria: How are you Abel?	
Abel: I´m fine. I am sorry ladies but I am leaving.	
Nuria: Yeah, of course.	
Anne: (Whispering) Do not worry, Once he left home, we will chat a little bit.	Protecting
Nuria: As you prefer Anne.	
Anne: Yes, yes. Because I do not want that he… As I was telling you, I try to be patient. For instance I say to him something I have to repeat it again and then I say to him: ‘I´ve already told you that’. I try to be patient but… I tell this to the GP because she noticed that I was a bit nervous. I am not sleeping very well so she recommended me to take some pills… Thus what I’ve told you that I am not dealing very well with it. I am not doing as good as I would like to do it but… (Abel came into the room). Sorry but I prefer he leaves because otherwise he…	Protecting Suffering Protecting
Nuria: As you both prefer.	
Anne: Now we are going to travel, we are going to (place). Once he concludes with the memory unit programme we will go to (place), thus he will get relax, he will see his relatives…	Preserving happiness
Nuria: Fresh air!	
Anne: Yeah, I think we need a change. However I do not feel as comfortable as I was before when we travelled together. He might	Needing a change Noticing changes

have some distractions while driving so… but we take care.	
[Anne talked to Abel before he leaves home]	
Nuria: By Abel, Take care yourself!	
Anne: By Abel. And this how we're doing Nuria. Everything I can do it for him I will do it. This way he does not see himself so…	Committed to family
Nuria: Anne, what happen when Abel noticed that something happened to him?	
Anne: He said 'don't say stupid things' He also answered with 'well well, well …' But he noticed and he still notices it.	Hiding Noticing the loss of self
Nuria: Did he try to hide them?	
Anne: Yeah, yeah. He started saying 'well, well...	Hiding
Nuria: I know, I know.	
Anne: Look, this happened yesterday. Yesterday it was 'San Juan'. His father called 'Juan' and his brother too. Then I said, 'let's see if he remembered that'. But he did not do it. Today he remembered it and he said: I did not call my brother… and I said to him: 'How did you forget it?' And he told me: 'I do not, I forgot it and that's it'. He forgot it. He forgets many things but… What can we do? (She start crying)	Hiding
Nuria: Don´t worry Anne. (I hold her hand)	
Anne: I have to accept it, but this hurts me a lot. Down this floor, I think is in the 6th floor, there is a men living… I think he is in his sixties, and he is… This is a complete shame! Oh my God! How bad this disease is! Thanks God that I have two children that care about us a lot	Suffering Committed to family
Nuria: You mentioned that during one first encounter. You said you feel really supported by them…	

Anne: Of course. Look, Adrian that lives in USA, he calls home every day: 'How is dad today?' Everything we need they are really willing to help with. But this is something that does not have solution. This is a shame. Now, that our children are adults, that we have very nice grandchildren… This is a little bit sad but… this is life.	Committed to family Feeling shame Feeling sadness
Nuria: Before, you mentioned that you feel nervous, don't you?	
Anne: Yeah, I wake up every day in the middle of the night… But look, few weeks ago I hear that in the church there would take place the sacrament of anointing of the sick and we both attended it. And the day I had the appointment with the GP and she told me: 'Anne, you had to be prepared, because this is life' I replied to her: 'I am prepared. Look how prepared we are that we have already received the extreme unction. I asked Abel: 'Do you want to go honey?' And he told me: 'If you want…' Before this sacrament was for dying people, but now we've received it being healthy.	Spiritual relief
[The phone rang and the interviewed was interrupted. Anne talked to Adrian, her son.]	
Anne: What am I saying? Oh yes, that this situation is a bit sad. Now that we are getting older the problems arise. But life is about it. First of all, taking care of the children. And later, when you think that your children are adults, they have a position and they are alright, this come to us. But, what should I say? Of course this has affected me. Because before we did many things	Feeling sad Everything is changing
Nuria: Do you feel you life has changed?	

Anne: Of course! Before we do lot of things, we travel… Now, I go to the memory unit with him… I do not know. Everything has changed, of course.	Everything is changing
Nuria: What about your relationship Anne?	
Anne: Everything. Everything is changing.	
Nuria: Everything	
Anne: Everything. Sometimes I wake up with good purposes but… But I am always keeping an eye on what he is doing. For example I like that he close the door before going to sleep, thus he realizes… thus he had things to do...	Watching
Nuria: You mean responsibilities?	
Anne: Exactly. Because I noticed that he lacks of initiative to do it by himself.	Noticing
Yesterday Adela told me: 'Mom, dad is not longer… you should take on the house finances' He has always managed the money. He has always managed our business. I have not cared about nothing. But my daughter told me that I should start taking on that responsibility. But look, I think that if I start doing this he is going to feel a little bit… what you think Nuria?	Changing roles Watching (Preserving)
Nuria: Anne, let me see if I understand your point, but you do not want to take his responsibilities off, do you? Because Abel might feel bad.	
Anne: Exactly Nuria. Look, when we go shopping I always say to him: 'you have to pay Abel', and I observe what he does. He use credit card as well… but at less this way he…you know?	Watching (Preserving)

Appendix 4.11 Example of memo

Example 1: operational memo (descriptive)

NVivo folder: Data collection- The Armendariz Family- Memo

Description: Memo 5. Anne does not freely express her feelings.

1st Interview: Interviewer: Nuria and Researcher (Ana); Interviewee: Abel, Anne and Adela

Throughout the interview I noticed that Anne felt uncomfortable when she expressed her own feelings on the situation. It seemed that she did not want to hurt her daughter and husband. The times she started crying, she immediately apologized for it. Moreover, episodes such as the above, lead me to think that in some way her daughter (mainly) and her husband prevented her from freely expressing her 'suffering'? Then: should I consider the idea of having an individual encounter with her? How should I offer this possibility to her? She already made me a kind of suggestion of this.

> *(Anne got emotionally affected when she was asked about her feelings on the new situation we previously talked about. However her daughter and husband reaction blocked her feelings' expression)*
> *Abel: Honestly, why are you crying?*
> *Adela: Mom, why are you acting like this? Dad is right at this time.*
> *Abel: Why honey?*
> *Anne: Sorry, I am a little weepy. Sorry about that.*
> *Researcher: What are you thinking Anne? What are you worried about?*
> *Anne: about everything, everything*
> *Adela: Mom, Dad is better that you. You are the one that now…*
> *Abel: Please Anne! If you're taking it worse than I'm doing.*
> *Anne: Alright; Then, that's it. I understand that my life has changed. That's it.*

What *'about everything, everything'* means? Anne used expressions such as *'mi life has changed'* or '*everything has changed'*… I need to further explore the hiding meaning of these expressions and what are the particular (explicit) changes that are integrated in the vital change she referred to.

Example 2: analytic memo (theoretical)

<u>NVivo folder: Data analysis- Categories- Everything changes</u>

Description: Initial ideas about the code *everything change* and new leads to further explore:

According to the Royal Academy of the Spanish Language dictionary *change* means: *1- Leave a thing or situation to take another; 2- Convert or move something to something else, often the opposite*.

Early stage of AD is a period in which first symptoms appear and makes evident to the family and, in which change, crisis, and adjustment and making decisions about care and care plan also take place. Family is usually the main support of the person with AD (carer). As a result, family life changes completely. *Caring* involves a change of lifestyle (participants refer to this as *'changing life'*, *'everything changes')* to which the family need to adapt. To do so they reorganize and modified certain aspect of life but: **<u>what are exactly those elements that families modify (redefine?) to adapt to the new situation? How this impact on the family dynamics</u>? To be explored in subsequent interviews**.

While for some families (e.g. the Armendariz) the prior dynamics of family may be stabilizing and protective elements against change, for others (e.g. the Blasco) it seems to be a barrier that even adds more difficulties. It is in these types of situations, when the group test their ties and relations, expose their strengths and weaknesses. **<u>What are the differences between one and other style?</u> <u>Does the perception of change depend on the degree of control that family has on the situation?</u>**

It seems that perceiving a change as positive is also associated to having the situation under control. Sometimes the negative perception of change is due to the inability to predict or control the situation (uncertainty) and not just the mere consequence that change may lead to the family. The Blasco for instance perceives Alzheimer's disease as a threat, thus its members do not only keep in mind the unintended consequences it brings but the inability to predict and control the future situation. Under this circumstance family expectations are broken. Confusion, fear, and loss of control may arise in the family. By contrast the Armendariz regards the condition as a challenge that ‘invites’ them to keep working together.

Explore:

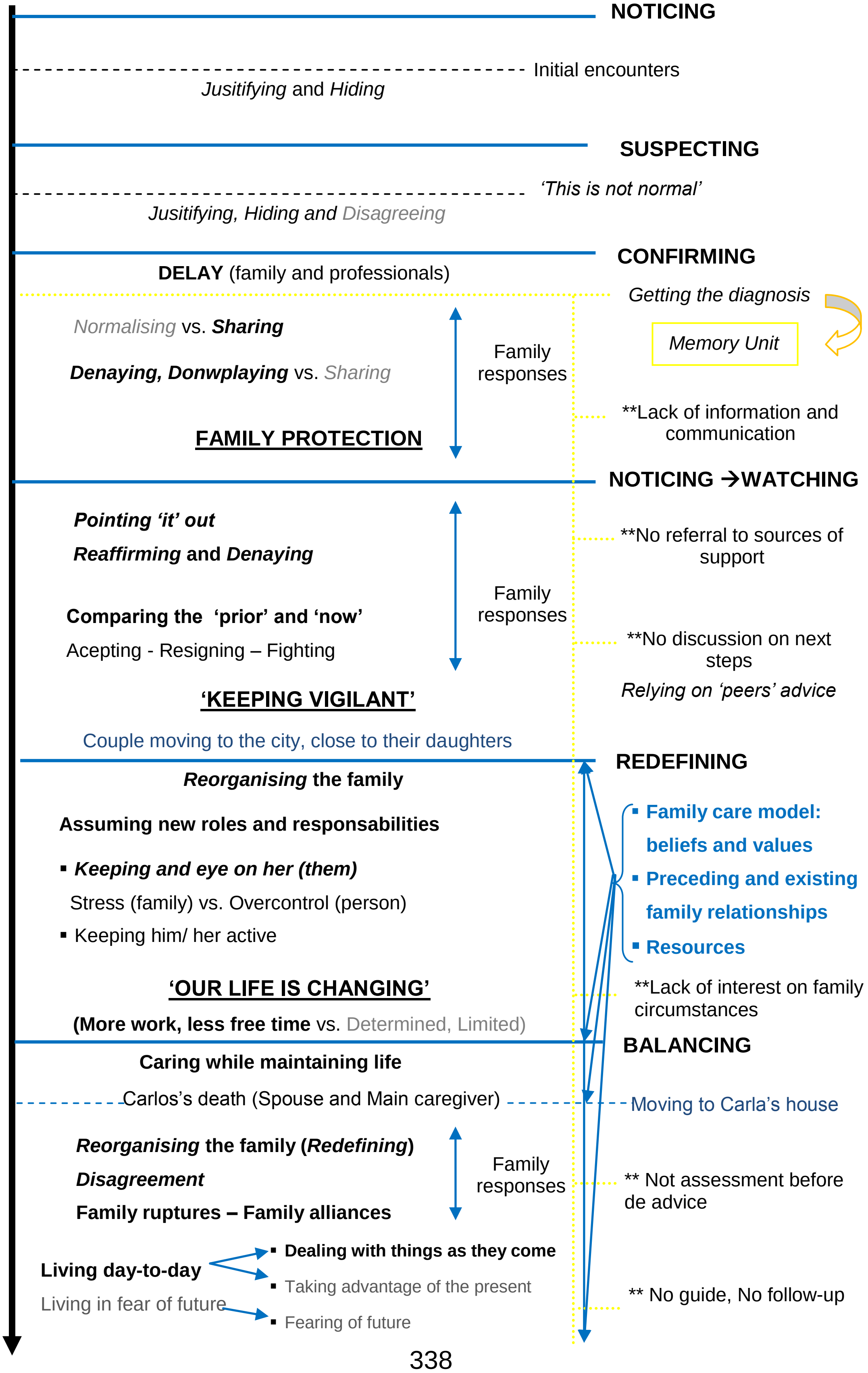
- How the dynamics of the family influence the way that families accept change and work to response to it.

- How the perception that the family had about the change (the onset of AD, the care demands, new responsibilities…) impact on present family functioning style.

- Does the changing nature of family life influence the expectations families have about future? What are these?

Appendix 4.12 Outline of the identified processes presented to participating families

Living with early stage AD: The (Cervera) family case study



NOICING

Initial encounters

Jusitifying and *Hiding*

SUSPECTING

'This is not normal'

Jusitifying, Hiding and Disagreeing

CONFIRMING

DELAY (family and professionals)

Getting the diagnosis

Memory Unit

Normalising vs. ***Sharing***

Denaying, Donwplaying vs. Sharing

Family responses

FAMILY PROTECTION

**Lack of information and communication

NOTICING →WATCHING

Pointing 'it' out

Reaffirming* and *Denaying

**No referral to sources of support

Family responses

Comparing the 'prior' and 'now'

Acepting - Resigning – Fighting

**No discussion on next steps

Relying on 'peers' advice

'KEEPING VIGILANT'

Couple moving to the city, close to their daughters

REDEFINING

***Reorganising* the family**

Assuming new roles and responsabilities

- ***Keeping and eye on her (them)***

  Stress (family) vs. Overcontrol (person)
- Keeping him/ her active

- **Family care model: beliefs and values**
- **Preceding and existing family relationships**
- **Resources**

'OUR LIFE IS CHANGING'

(More work, less free time vs. Determined, Limited)

**Lack of interest on family circumstances

BALANCING

Caring while maintaining life

Carlos's death (Spouse and Main caregiver)

Moving to Carla's house

***Reorganising* the family (*Redefining*)**

Disagreement

Family ruptures – Family alliances

Family responses

** Not assessment before de advice

Living day-to-day

Living in fear of future

- **Dealing with things as they come**
- Taking advantage of the present
- Fearing of future

** No guide, No follow-up

Appendix 4.13 Consent Form of the focus group participants

I, ……………………………………, declare I was informed by Nuria Esandi Larramendi about the study aimed at explore the experience of families living with Alzheimer's disease (early stage).

Focus Group

I understand that if I give consent I will take part on a 'focus group' with other relatives of people with Alzheimer's disease, with the aim of sharing my experience and discussing about the emerging theoretical model of the study and thus seeing if it makes sense to me.

The researcher ensures absolute confidentiality, by not revealing personal information and preserving my anonymity and privacy of throughout the study, especially at the time of the dissemination of results.

Likewise Nuria Esandi explained me that the focus group discussion will be audio recorded if I previously allow it, to facilitate the subsequent analysis of data. However once the study concludes the recordings will be destroyed.

Therefore I declare that:

☐ I agree to take part in the study and this research interview to be taped-recorded.

☐ I agree to take part in the study but <u>DO NOT</u> agree this research interview to be taped-recorded.

....

(Participant name and signature)

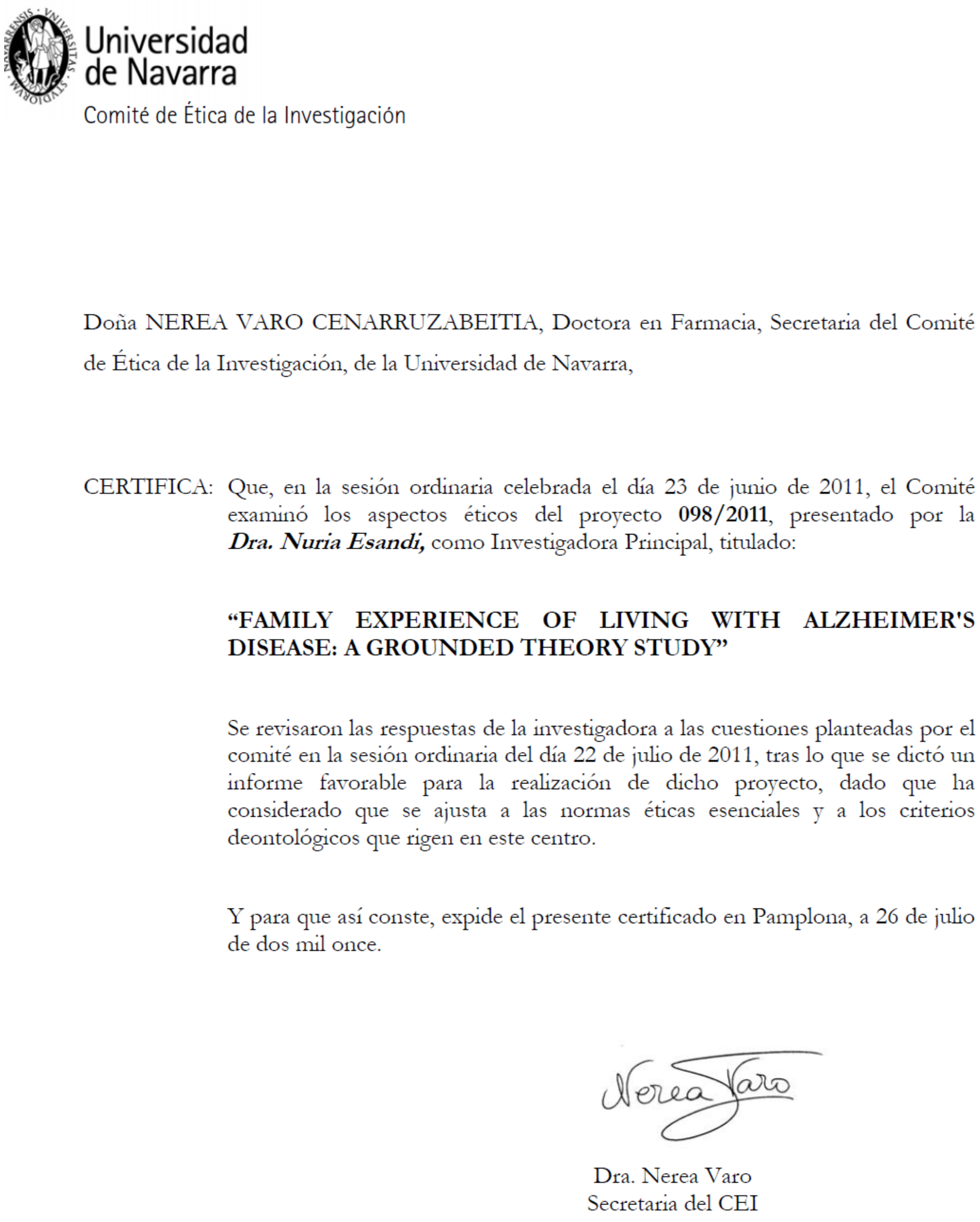
....

(Researcher name and signature)

....

Date

Appendix 4.14 Ethical Approval



Universidad de Navarra
Comité de Ética de la Investigación

Doña NEREA VARO CENARRUZABEITIA, Doctora en Farmacia, Secretaria del Comité de Ética de la Investigación, de la Universidad de Navarra,

CERTIFICA: Que, en la sesión ordinaria celebrada el día 23 de junio de 2011, el Comité examinó los aspectos éticos del proyecto **098/2011**, presentado por la ***Dra. Nuria Esandi,*** como Investigadora Principal, titulado:

"FAMILY EXPERIENCE OF LIVING WITH ALZHEIMER'S DISEASE: A GROUNDED THEORY STUDY"

Se revisaron las respuestas de la investigadora a las cuestiones planteadas por el comité en la sesión ordinaria del día 22 de julio de 2011, tras lo que se dictó un informe favorable para la realización de dicho proyecto, dado que ha considerado que se ajusta a las normas éticas esenciales y a los criterios deontológicos que rigen en este centro.

Y para que así conste, expide el presente certificado en Pamplona, a 26 de julio de dos mil once.

Nerea Varo

Dra. Nerea Varo
Secretaria del CEI

APPENDICES CHAPTER 5

Appendix 5.1 Socio-demographic characteristics of people with AD

ID.	GENDER	AGE	EDUCATION	OCUPATION	HOUSING	MMSE *GERD	DX (YEAR)
Armendariz (Abel)	Male	73	College	Retired (Business and management)	Urban Area (Living with his wife)	MMES 22 Gerc 96	Nov. 2011
Blanco (Barbara)	Female	74	Primary	Housewife	Urban Area (Living alone)	MMES 21 Gerc72	March. 2011
Cervera (Carmen)	Female	77	Primary	Housewife	Urban Area (1.Living with her husband; 2- Living with her daughter)	MMES 19 Gerc 85	Nov. 2011
Dominguez (Daniela)	Female	85	Primary	Retired (Services and hostelry)	Rural Area (Living alone)	MMES 21 Gerc 80	Sep. 2012
Estevez (Elena)	Female	78	High	Retired (Administration)	Urban Area (Living with her daughter)	MMES 18 Gerc 89	Jan. 2012
Gonzalez (Gabriel)	Male	77	High	Retired (Transportation)	Urban Area (1.Living alone; 2.Living with his daughters)	MMES 22 Gerc 72	June 2012
Jimenez (Justina)	Female	72	Primary	Housewife (Hostelry-business owner)	Rural Area (Living with her husband)	MMES 18 Gerc 67	Jan. 2013

***GERD:** GERMICIDE, protocol for basic neuropsychological assessment, Spanish Society of Neurology.

Appendix 5.2 Socio-demographic characteristics of relatives

FAM ID.	FM. INTERVIEWED	AGE	EDUCATION	OCUPATION	STATUS/ HOUSING
Armendariz	Anne. Wife Adela. Daughter	75 42	Elementary College (Psychology)	Housewife Unemployed	Living with husband Own house; Married, 2 children
Blasco	Bea. Daughter Beatriz. Daughter Blanca. Daughter	47 43 38	Primary Primary High	Unemployed Unemployed Unemployed	Own house; Married, 2 children Own house; Married, 2 children Own house; Married, 1 child
Cervera	Carlos. Husband Carla. Daughter Cecilia. Daughter Camila. Daughter	79 50 47 43	Primary Primary Primary High	Retired (Services) Health assistant/ leave of absence Unemployed Unemployed	Living with her wife Own house; Married, 2 children (Her mother moved to lived with her) Own house; Married, 2 children Own house; Married, 1 child
Dominguez	David. Son Denia. Goddaughter	53 62	Primary Primary	Disability pension (Retired) Retired	Own house; Divorced, 1 child Own house; Married, 2 children
Estevez	Elisa. Daughter	48	College (Finances)	Economist	Own house; Married, no children (She (+ her husband) lived with her mother from Monday to Friday)
Gonzalez	Gemma. Daughter	52	College (Teaching)	Elementary school teacher/ leave of absence	Own house; Married, no children
Jimenez	Julieta. Daughter Jimena. Daughter	46 38	Primary College (Psychology)	Business owner (auto-motion) Psychologist	Own house; Married, 2 children Own house; Couple, no children

Appendix 5.3 Socio-demographic characteristics of focus group participants

ID.	GENDER	AGE	RELTIONSHIP	EDUCATION	OCUPATION	HOUSEHOLD	YEARS WITH AD Dx.
FG.1							
Idoia	Female	57	Daughter (mother)	High school	Public services (Post office) Full-time	Urban Area Living with her mother	7 year
Inma	Female	56	Daughter (mother)	Job Training	Administrative Full-time	Urban Area Living with her mother	6 years
Isabel	Female	42	Daughter (mother)	University	Unemployed	Rural Area Weekend, living with her mother	4 years
Irena	Female	56	Daughter (mother)	Primary school	Unemployed	Urban Area Daily visit to her mother	3 years
Ilda	Female	48	Daughter (mother)	University	Pharmacist Full-time	Rural Area Regular visits to her mother (Nursing-home)	8 years
FG.2							
Leonor	Female	38	Daughter (father)	University	Unemployed	Urban Area Living with father	5 years
Lisa	Female	45	Daughter (mother)	Job Training	Receptionist Full-time	Rural Area Regular visits to her mother	4 years
Laura	Female	51	Daughter	University	Pharmacist	Urban area	4 years

			(mother)		Part-time	Regular visits to her mother	
Leo	Male	65	Husband (wife)	High school	Retired	Urban Area Living with her wife	5 years
Lucas	Male	75	Husband (wife)	Primary school	Retired	Urban Area Living with her wife	4 years
FG.3							
Marta	Female	54	Daughter (mother)	Job Training	Family support worker Part-time	Urban Area Living with her mother	5 1/2 years
Maddie	Female	49	Daughter (mother)	Job Training	Administrative Part-time	Rural area Regular visits to her mother	4 years
Magdalena	Female	33	Daughter (mother)	-	Full-time	Urban Area Living with her mother	2 years
Maria	Female	42	Daughter (mother)	Job Training	Occupational disability	Urban Area Regular visits to her mother	8 years

Appendix 5.4 Summary table of the family case studies

FAM ID.	PRIOR DYNAMICS	SET OF FAMILY VALUES	SUPPORT	VISION FOR FUTURE	SALIENT BEHAVIOUR	CURRENT DYNAMICS
Armendariz	Closeness Strong family ties	Religious orientation Commitment to family Appreciation Care based on love to each other	Intra-family support	Living day-to-day	Protection Agreement Affective involvement	Closeness and Satisfactions with care
Blasco	Conflicting Disengagement	Individuality Care based on a sense of duty	Intra-family support	Living in fear of the future	Disagreement Alliances	(Partial) Closeness and yet Difficulties in care
Cervera	Closeness Strong family ties	Commitment to the family Appreciation Care based on love to each other	Intra-family support	Living day-to-day	Disagreement Alliances	(Partial) Conflicting and Difficulties in care
Dominguez	Conflicting Disengagement	Individuality Care based on a sense of duty	External resources Intra-family support	Living in fear of the future	Disagreement Alliances	Conflicting and Difficulties in care
Estevez	Closeness Friendly relationships	Religious orientation Commitment to the family Respect Care based on a sense of co-responsibility	External resources and Intra-family support	Living day-to-day	Agreement Cooperation	Closeness and Satisfactions with care

Gonzalez	Closeness Friendly relationships	Commitment to the family Respect Care based on a sense of co-responsibility	Intra-family support	Living in fear of the future	Disagreement Poor Communication	Conflicting and Difficulties in care
Jimenez	Closeness Strong family ties	Commitment to the family Appreciation Care based on love to each other	Intra-family support	Living day-to-day	Disagreement Strong Emotional impact	Conflicting and Difficulties in care

Definition of concepts

- **Closeness; strong family ties:** Members shared a deeper level of understanding, trust and affection.
- **Closeness; friendly relationships:** Members shared affection or esteem and engaged in mutually helping behaviours.
- **Conflicting; disengage:** Members rarely came into contact, but when they were in each other's presence, they argued and were hostile towards one another.

- **Religious orientation:** Families were guided by an underlying moral or value system shared by all members.
- **Commitment to the family:** Each family member was valued, supported and sustained, while at the same time members were committed to the family as a unit.
- **Individuality:** Individual needs and activities are accentuated
- **Appreciation:** Doing things that were positive from the other person’s perspective, just for their sake, not merely as a strategy for ‘buying their love’. Appreciation also implied encouragement of members. This is a little more positive (broadly speaking) than respect.
- **Respect:** Members regarded each others with consideration

- **Care based on love.**
- **Care based on a sense of co-responsibility:** Caregiving was a shared responsibility and assumed to correspond other members of the family (correspond to a sister; correspond to my mother, gratitude).
- **Care base on a sense of duty:** Caregiving was regarded as (social) moral obligation; for example children must care for older parents.

- **Living day-to-day:** Families made efforts and did their best possible each day.
- **Living in fear of future:** Families feared the unknown and the unseen, principally because of the unstable family situation and the struggling past dynamics.
- **Protection:** Attitude aimed at guarding and preventing members from suffering.

- **Disagreement:** Conflict happened when family members had different views or beliefs that clashed. Sometimes this occurred when people misunderstood each other. Issues of conflict that were not resolved peacefully led to arguments and resentment among members. Occasional conflict could be part of family life; however, ongoing conflict resulted stressful and damaging to family relationships.
- **Agreement:** Coming to mutual arrangements in the family.

- **Satisfaction with care:** The positive dimension of the experience. Families were strengthened through care activity. They remained or became united.
- **Difficulties in care:** The less positive dimension of the experience. For these families caring was a stressful experience that took them to gave up aspects of their life. Feelings such as stress, determination and tiredness were displayed.

  It would be worth to note that both difficulties and satisfactions could co-exist and occurred simultaneously. However family categories were attached according to the more accentuated experience at the time of the study.