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THE LIVED EXPERIENCE OF CARING FOR
A FAMILY MEMBER WITH DEMENTIA

A QUALITATIVE STUDY

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Abstract

The aim of this interpretative phenomenological analysis is to elucidate the experience of caring for a family member with dementia. Semi-structured interviews were conducted with six caregivers (four females, two males). Four of the caregivers were the child (three daughters, one son) and the others were the spouses (one husband, one wife) of a relative with dementia. The interviews were audio-recorded, transcribed verbatim and analysed. The findings suggest that the caregivers’ life changed dramatically from the moment their relative was diagnosed. Different factors determined why caregivers decided to pursue this role. As time passed, caregivers became so immersed with their relative’s care, sometimes even at their own expense, that they experienced a downfall in their overall quality of life. As dementia progressed, the caregivers experienced several kinds of losses with caregivers grieving mostly the psychological loss of their loved one. Despite this tough situation, caregivers managed to cope effectively and identified several positive aspects of caregiving. These findings will be discussed in light of the literature review. Recommendations for future research and practice will also be discussed.

Keywords: dementia, family caregivers, quality of life
Dedicated to
all caregivers for
their unconditional love
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Chapter 1

Introduction

Background to study

“A life that concludes without the final chapter, without the time to grow old and gain perspective, often seems bitterly incomplete but the greatest loss, the greatest dehumanisation is to grow old without possession of your mind” (Grollman & Kosik, 1996, p.xi).

I have always shown a keen interest in the phenomenon of memory loss and always wondered what it would feel like if a loved one had to lose all the memories they have had of the people they love. This has instilled in me the interest to explore what relatives of a person with dementia go through. My own personal experience played a major role in helping me choose family caregiving as the subject for this study. Although I do not have any relatives with dementia, I had a brief experience of caring for a relative. Through this, I developed an admiration for dementia family caregivers for their courage in pursuing this role with unconditional love and patience for an extended period of time. These thoughts and experiences form the rationale behind my choice of study.

Dementia is a “major predictor of mortality and morbidity in the elderly” (Scerri, Abela, & Innes, 2010, p.6). The most common form of dementia is Alzheimer’s disease. Other common forms are; vascular dementia, lewy body dementia and frontotemporal dementia. It is uncommon that an individual has only one form of dementia, since these tend to coexist in mixed forms (World Health Organisation, 2012). According to the WHO (2012), the global prevalence of individuals living with dementia in 2010 was 35.6 million. This number is expected to double by the year 2030 and triple by the year 2050 reaching a peak of 115.4 million people with dementia.
The estimated prevalence in the Maltese Islands is also expected to increase. In 2005, the number of local dementia cases was 4,072 where figures indicate there will be an estimated total number of 6,347 individuals with dementia in 2025, adding up to 2% of the population (Abela, Mamo, Aquilina, & Scerri, 2012). This increase in the number of dementia cases results in an increase in the number of dementia family caregivers.

**Research aim**

The research question is: “what is the lived experienced of caring for a family member with dementia?” The aim of this study is to elucidate the experience of caregivers who have been or are still caring for a relative with dementia. Since this study focuses on the lived experience of family caregivers, the caregivers’ own subjective experience, perceptions and feelings are significant to answer my research question. Hence, I decided to use interpretative phenomenological analysis (IPA) as described by Smith, Flower and Larkin (2009) to explore how caregivers make sense of their own experience.

**The conceptual framework**

This research is guided by the stress model of Pearlin, Mullan, Semple and Skaff (1990). This model consists of several components that relate to family caregiving. It takes into account the background and contextual factors of the caregivers, the stressors that exert a demand on the caregivers (e.g. burden) and how these affect their well-being and quality of life (QoL). Moreover, they also discuss mediators of stress that include coping strategies and social support (as cited in Iecovich, 2008). I have decided to use this model because it takes a holistic picture of the caregiving experience by considering the caregiving process, the impacts this has on the caregivers’ QoL and the resources available to cope with such a situation.
Significance of study

As I have previously stated, the number of dementia cases in Malta is increasing, therefore the number of carers, caring for a relative with dementia will also increase. Hence, this study within its limitations will attempt to give a voice and meaning to the caregivers’ experience. It will also attempt to increase awareness about the experience of dementia family caregivers. The findings might also provide insight into the subject of dementia family care and therefore contribute knowledge for further studies.

Definition of terms

“Dementia” refers to a condition of various etiologies and forms which affect “multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning” (American Psychiatric Association, 2000, p.148). For the purpose of clarity, in this study, I will focus on caregiving of a relative with dementia who is from sixty years old or over since according to WHO (2013) this is considered to be the beginning of old age.

Overview of chapters

This chapter will be followed by a detailed account of the literature on family dementia caregiving. The rationale for the methodology employed will be discussed in chapter 3. In chapter 4, I will present the findings of the six semi-structured interviews. I will then discuss these in light of the literature review in chapter 5. In the last chapter I will give an overview of the study with its strengths and limitations. Recommendations for future research and practice will also be discussed.
Chapter 2

Literature Review

Introduction

In this chapter I am going to present the literature on dementia family caregiving. I will highlight how in Malta, age-related issues such as dementia are becoming of a concern to society and present information on family caregivers. The process of caregiving will be outlined as the backdrop to understand issues related to negative outcomes of caregiving, QoL and mediators of stress. Issues regarding positive aspects of caregiving will also be discussed.

Demographic changes in Malta

The shift in demography has resulted in a progressive increase in the elderly population due to an increase in life expectancy (Innes, Abela, & Scerri, 2011). According to the National Statistic Office (2012) 16.3% of the population are persons aged 65 and over, an increase of 2.6% from 2005. Hence, age-related issues are becoming more significant in the Maltese society as with advancing age; severe and long-term illnesses tend to increase, requiring attention for an indefinite period of time. This happens especially when chronic conditions impact the individuals’ level of dependency, such as in the case of dementia (Triosi & Formosa, 2006).

For the people with dementia and their caregivers, the behavioural and psychological changes are the most relevant. This is because dementia impacts the individuals’ ability to live independently and autonomously (WHO, 2006). The symptoms of dementia pose a great psychological toll on family members as now they have to accept the fact that their loved one is now a patient, unable to recognise them (Grollman & Kosik, 1996). Foreign literature on
caregiving amongst relatives is well documented. This experience is often described as a life changing and hardship situation, full of responsibilities (Butcher, Holkup, & Buckwalter, 2001).

In Malta, I did not find any information on the number of dementia family caregivers. Local literature on informal caregiving is documented mostly in unpublished students’ dissertations (e.g. Cilia Custo’, 2012). However, literature on family dementia care is scarce as the only research available focus on the medical aspect (Innes et al., 2011). The first local published research was made by Innes et al. (2011) where they examined the family organisation of care and caregivers’ experience with dementia.

The informal caregivers

Generally, there is one main caregiver who provides all the care for the dependent relative (D’Amato, 1995). Brodaty and Donkin (2009) indicate that females are more likely to pursue the caregiving role than males.

According to Triosi and Formosa (2006), the majority of relationships between carer and care-recipient are that of wife-husband and child-parent. D’Amato (1995) explains that since there is a higher degree of intimacy between spouses and children certain task like giving a bath are much easier for them to assume than any other relative.

Research highlights that the predominance of these dyads suggest that spouses feel obliged to live up to their marital vows and that children consider caregiving as their natural obligation and duty (Triosi & Formosa, 2006; Innes et al., 2001). Moreover, carers might also feel that the caregiving role is an opportunity to reciprocate the care provided by their relative, especially if the relative is a parent (Willoughby & Keating, 1991; D’Amato, 1995).
According to Aneshensel, Pearlin, Mullan, Zarit and Whitlatch (1995) spouses and children are at greater risk of “role captivity” (p.80), defined as the obliged feeling to be a caregiver. This does not refer to the demands of caregiving but it “exists when a person feels compelled to be and to do one thing, while preferring something else” (p.80).

**Frequency of providing care**

The care provided by the informal caregivers is continuous and on a daily basis (Triosi & Formosa, 2006). This is because the care-recipient is fully dependent on the carer especially in the advanced stage of dementia. In their study, Triosi and Formosa (2006) illustrate that 65.6% of the caregivers spent all day taking caring of their relative who was either bedridden and/or with dementia. The authors report that some of the interviewed carers even woke up at night to assist their relative’s needs.

**The caregivers’ experience**

An understanding of what caregiving entails is significant to gain insight into the caregivers’ experience throughout the progression of dementia. Qualitative studies on caregivers’ experience are limited. However, the research present is consistent with what caregivers pass through.

**Witnessing changes in the relative**

Experiential studies suggest that at first caregivers are uncertain about the behavioural and personality changes in their relative. Despite this, they feel reluctant to seek help. Instead they attribute these changes to something wrong within their relationship as at this stage, caregivers feel emotionally distant from their relative (Pfeiffer, 1999; Willoughby & Keating, 1991). Dupuis, Epp and Smale (2004) report that when caregivers seek medical attention, the most
frustrating experience is the struggle involved in getting a proper diagnosis and when they manage, they find it hard to accept it. Shock, disbelief and horror were the most common first reactions upon hearing the diagnosis though caregivers also feel relieved because they have an explanation for their relative’s change (Kuhn, 1998; Grollman & Kosik, 1996). When caregivers decide to take up this role, the doctors either encourage or discourage them to put their relative in an institution (Cilia Custo’, 2012).

**Providing care at home**

During the early stages of dementia, the relative can still live autonomously. Hence the carer is more of a companion than a caregiver at this stage. As dementia progresses, the relative’s ability to communicate deteriorates making it very difficult for caregivers to understand their relative’s needs (Pfeiffer, 1999). However, Loukissa, Farran and Graham (1999) indicate that as carers grow familiar with dementia, they manage to adopt different strategies by making any form of adjustments for the sake of their relative.

Similarly, Kuhn (1998) suggests that caregivers perceive their relative’s dependency as very challenging because they have to coordinate their lifestyle to suit their relative’s needs. This results in performing activities which carers feel unbearable (Aneshensel et al., 1995). According to Butcher et al. (2001), despite the stress and frustration, caregivers still respond to their relative with a loving attitude and strive to keep things normal as much as possible.

This all-consuming role ends when caregivers acknowledge the fact that they need help. Research indicates that there is a point with dementia where carers feel unable to meet the demands of caregiving (Willoughby & Keating, 1991; Pfeiffer, 1999). Consequently, according to Willoughby and Keating (1991) caregivers decide to institutionalise their relative even though
they experience feelings of helplessness and sadness because they can no longer cater for their relative. Austrom and Hendrie (1990) suggest that caregivers feel this way due to the fact that this role becomes part of their identity.

**Experiencing anticipatory grief**

Before the physical death of the relative, caregivers experience several losses throughout the progression of dementia such as the loss of their relative’s personality (Austrom & Hendrie, 1990). Cilia Custo’ (2012) also indicates a loss of relationship, as the carers start to perceive the relative as a child. Consequently, caregivers find it more difficult to provide care for someone who no longer retains an emotional bond (Austrom & Hendrie, 1990). Doka (2010) argues that caregivers find it difficult to deal with the behavioural and psychological manifestations of dementia as these represent the loss of their relative’s personality and hence exacerbate feelings of grief. Similarly, Holley and Mast (2010) explain that these manifestations are a predictor for anticipatory grief. The same authors state that caregivers also experience secondary losses such as the loss of one’s social life. These losses are continuous through the progression of dementia and hence “the caregivers’ grief may wax and wane, while they recycle again and again through the grief experience” (Ponder & Pomeroy, 2008, p. 15).

**Caregivers’ burden**

George and Gwyther (1986) define caregivers’ burden as “the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults” (p.253). Since burden is multidimensional it can either refer to the negative consequences arising from activities of daily living or to how caregivers perceive such a situation (Braithwaite, 1992).
A study by Pierce, Ader and Peter (1989) suggests that burden is associated with the relative’s level of impairment, frequency of care and activities performed. Raccichini, Catellani, Civerchia, Fioravanti, and Scarpino (2009) indicate that spousal caregivers are the most likely to feel burdened when compared to the children of the care-recipient and females tend to experience more emotional burden than males. On the contrary, Bialon and Cole (2011) argue that both genders indicate a decline in their overall health especially if they do not have any social support.

According to Triosi and Formosa (2006) the consequences of burden generally include “depression, psychological distress, lowered life satisfaction, interpersonal conflict, social isolation and stress-related physical health complaints” (p.44). This burden does not seem to decrease even if their relative is institutionalised (Pierce et al., 1989). Martin-Cook, Trimmer, Svetlik and Weiner (2000) suggest that caregivers are able to feel less burdened when they focus on the positive feeling of fulfilling an important job.

**Caregivers’ quality of life**

QoL is defined as the “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1997, p.1). According to Vellone, Piras, Venturini, Alvaro and Cohen (2012) caregivers consider family unity, autonomy, freedom, tranquillity and overall health crucial to a better QoL. The same authors indicate that caregivers express that fear of the unknown and having less time for themselves made it worse.

**Impacts on work and social life**

Burden affects the caregivers work and social life negatively (Iecovich, 2008; Ekwall, 2004). Triosi and Formosa (2006) indicate that although work is significant to maintain the household,
the strain of work and caregiving is unbearable. A study by the National Alliance for Caregiving (2009) in the United States illustrates that when it becomes difficult for caregivers to juggle the two, a sizeable amount of caregivers (70%) report making changes such as reducing the working hours, changing job conditions or leave work altogether. The study adds that the amount of adjustments caregivers make at work is determined by how intensive the caring situation is.

According to Rogers (2001) caregivers are also deprived from the opportunity to foster relationships with others as they experience a loss of leisure and social life. One reason that the carers’ social life becomes severely impacted is due to the long hours spent caregiving. This affects their relationship with their friends/relatives as they cannot go out (Triosi & Formosa, 2006). Hence, caregivers have little opportunity to develop or maintain new social relationships. On the other hand, friends/relatives might socially marginalise them due to the lack of knowledge about the demands of dementia caregiving (Dupuis et al., 2004).

**Impacts on psychological and physical health**

Schulz and Beach (1999) indicate that when compared to non-caregivers, dementia caregivers are more susceptible to high levels of anxiety and depression. In fact, anxiety disorders have been found to impact one in three dementia caregivers (Akkerman & Ostwald, 2004).

Ory, Yee, Tennstedt and Schulz (2000) suggest that the majority of caregivers experience physical problems. Vitaliano, Echeverria, Yi, Phillips, Young and Siegler (2005), indicate that caregivers are at an increased risk for obesity and insulin resistance. These factors have been found to be related to an increased risk of mortality amongst family caregivers (Schulz & Beach, 1999). Furthermore, when compared to non-caregivers, caregivers tend to engage in less health-promoting, self-care behaviours (Acton, 2002).
Mediators of Stress

As I already highlighted, caregivers experience many emotions whilst pursuing this role. The feelings range from denial, fear, guilt, anger, stress, depression, anxiety, burden and frustration (Grollman & Kosik, 1996; Butcher et al., 2001). To overcome these feelings, the caregivers employ their own coping strategies to deal with stress. This involves an effort to change the circumstance so as to make it more manageable (Taylor, 2009). The way caregivers handle stress influences their capacity to live a good QoL (Ekwall, 2004).

Stress models have been applied as an attempt to understand how different individuals deal with stress. The transactional model of stress by Lazarus and Folkaman (1984) indicate that the way individuals interpret a specific event or situation determines an individual’s reaction.

In this section, I am going to discuss different coping strategies employed by family dementia caregivers. Emphasis will be given to social support and spiritual coping since family and religious values are deeply ingrained in the Maltese society (Tabone, 1995).

Problem- and emotion-focused coping strategies

Problem-focused forms of coping are “directed at defining the problem, generating alternative solutions, weighting the alternatives in term of their costs and benefits, choosing among them and acting” (Lazarus & Folkman, 1984, p.152). In contrast, emotion-focused coping involves “efforts to regulate emotions experienced because of the stressful event” (Taylor, 2009, p.181).

A study by Bowd and Loss (1996) illustrate that sixty-eight caregivers dealt with the caregiving role by using both forms of strategies that include: self-reliance, independence,
praying, reading and talking to their family. Strategies such as assigning blame, crying and expressing anger were the lowered rank coping strategies. This is consistent with the findings of Pierce et al. (1989) as they indicate that caregivers of a relative with dementia use both types of coping strategies. Taylor (2009) suggests that individuals who employ different coping strategies can cope better than those who always use the same type of strategy.

There are several reasons why employing both of these coping strategies is useful. Emotion-focused coping helps caregivers reappraise their situation as it gives them courage to maintain hope and optimism (Lazarus & Folkman, 1984). On the other hand by employing problem-focused coping the carers are more likely to benefit from a better psychological QoL (Pattanayak, Jena, Vibha, Khandwelwal, & Tripathi, 2011). Pattanayak et al. (2011) highlight that the most beneficial coping strategy employed by caregivers was social support as it contributed to a better overall QoL.

**Gaining social support**

The care given by a relative is qualitatively different from the care given by a paid worker or agency. The latter is defined as the assistance provided by support groups/agencies such as the “Malta Dementia Society”, whilst the former is the assistance provided by family members out of feelings of love and obligation towards their frail, elderly relative (Kaufman, Kosberg, Leeper, & Tang, 2010).

Studies illustrate that social support predicts caregivers’ burden and overall life satisfaction. This suggests that when caregivers seek social support, they are more likely to experience an increase in life satisfaction and decrease in burden (Kaufman et al., 2010; Lai & Thomson, 2011).
Caregivers living in large countries might find it difficult to gain support due to long distances. This is not the case in Malta. As Tabone (1995) explains, Maltese families live close to each other. His study indicates that 66.3% of families live in the same place as their family of origin. Another point worth noting is the importance of unity within the Maltese families. This aids the availability of social support, as Maltese families tend to share everything, especially life adversities (Tabone, 1995).

**Spirituality and religious coping**

Stuckey and Gwyther (2003) define ‘religion’ as a set of beliefs governed by faith and ‘spirituality’ as a “search for meaning in life” (p.291). According to Triosi and Formosa (2006), the Maltese consider the church values and spirituality as a form of support. Similarly, Stolley, Buckwalter and Koeing (1999) argue that trusting in God and prayer is an effective way for dementia caregivers to deal with their situation. This might be because religion and spirituality is perceived by the carers as a hope for the future, a source of strength, security and guidance (Stuckey & Gwyther, 2003; Snyder, 2003). According to Duggleby, Swindle, Peacock and Ghosh (2011), hope predicts how caregivers perceive their overall QoL.

**Caregivers’ gain**

Different individuals have different ways of coping through life adversities (Lazarus & Folkman, 1984). Hence, one might be able to cope with the demands of caregiving whilst another will be unable to cope even if it is the same situation. According to Walsh (2003) “the ability to withstand and rebound from disruptive life challenges” (p.399) is known as resilience. Little information was found on resilience with relevance to dementia family caregiving. However, despite being an under researched area, I think that the concept of resilience can help
explain why different caregivers gain more from their experience than others. In fact, Scott (2010) indicates that an increase in caregiver’s resilience results in a decrease in burden.

According to Kramer (1997) “caregivers gain” (p.218) refers to any positive outcome derived from being a caregiver. The concept of caregivers gain is understood in relation to positive aspects of caregiving (PAC) as it can lessen the impact of all the negative consequences that arise from caregiving (Semiatin & O’Connor, 2004). Dupius et al. (2004) report satisfaction, gratification, pride, sense of reciprocity of care, personal growth, sense of purpose and meaning as the crucial constituents of PAC. Cohen, Colantino and Vernich (2002) in their study indicate that 73% of caregivers were able to identify at least one PAC. The authors specify that positive appraisal of the situation is associated with lower burden and hence a better QoL.

**Conclusion**

Having reviewed relevant literature, I have gained better insight to the process of caregiving, how they cope with such a situation and the positive and negative impact which caregiving has on their overall QoL. In the following chapter, I will provide an explanation and rationale for the methodology employed in this research.
Chapter 3
Methodology

Introduction

This chapter provides a rationale for the methodology employed within this research. I am going to present information about the participants and the method of data collection. The procedure carried out for this research will be outlined throughout the aforementioned sections. A detailed explanation of how the data was analysed, will also be provided. Issues related to reflexivity, ethical considerations and academic rigour will also be discussed.

Aim and the research question

The main research question for this study is: “What is the lived experience of caring for a family member with dementia?” The purpose of this study is to explore and gain understanding of the carers’ feelings, perceptions and experience that they go through whilst caring for their relative. I am also interested in how this situation impacts their QoL and how they cope with it.

The method of inquiry

In this research the participants’ subjective experience is significant to answer the research question therefore a qualitative approach was the most suitable method to reach this aim. According to Willig (2001), this approach is concerned with how individuals interpret and experience a particular event in their life whilst at the same time aims to give a voice to experiences that are dismissed.
The methodology

For this study, I decided to use Interpretative Phenomenological Analysis (IPA) as described by Smith, Flower and Larkin (2009). In accordance with my research, IPA’s main aim is to understand how people perceive and make sense of their experience (Smith et al., 2009).

This study adopts a social constructivist perspective since this position asserts that multiple realities of an experience exist and these must be understood within an individual’s context (Creswell, 2007). The main theoretical underpinnings of IPA are phenomenology, hermeneutics and idiography. In line with my research, phenomenology is concerned with capturing the essence of this experience (Smith et al., 2009).

IPA acknowledges the research as a process where as a researcher I have an active role in this research. Hence, a double hermeneutic is involved where I, as the researcher have to make sense of the participants’ experience whilst at the same time try to understand this from their internal frame of reference (Smith & Eatough, 2007). To achieve this type of understanding, I need to be self-aware of how my biases and subjectivity can hinder the research process (Smith et al., 2009). These will be discussed in the reflexivity section.

IPA is an idiographic mode of inquiry where it is concerned with understanding and analysing a particular experience (Smith et al., 2009). This approach is suitable because I am specifically interested in the unique experience of being a dementia family caregiver.

The participants

The participants were recruited on a voluntary basis from the “Malta Dementia Society.” Purposive sampling was used for this study to obtain six participants. In this type of sampling the
participants were selected on the basis of criteria to ensure a fairly homogenous sample (Smith & Eatough, 2007). The eligibility criteria that was needed for the inclusion of participants in this study, is presented below:

i. Carers who have been or are still the caregivers of a relative with dementia who is either still living at home or has been/still living in a nursing home. The latter was included because over the years given the severity of dementia many caregivers opt to institutionalise their relative.

ii. The caregiver had to be either the spouse or the child of the relative with dementia. The reason for this is because spouses and children of a person with dementia share a high level of emotional bond, more than any other relative. Moreover, certain activities of caregiving are much easier for them to assume than any other relative (D’Amato, 1995).

iii. The caregivers must have been providing care for at least three years. The criterion was included because over the years caregivers might have come to terms with their situation (Cilia Custo’, 2012). Since this could not be guaranteed, as a precaution, if any of the participants needed further counselling I planned to refer them to the “Malta Dementia Society.”

The participants who met these eligibility criteria were contacted through a letter sent by the “Malta Dementia Society” on my behalf due to the data protection act. Those participants who were interested in having part in the research contacted me directly through phone or e-mail.

Four females and two males participated in this study. Before the start of each interview, I gave the participants a consent form where I assured them about all ethical considerations which will be discussed later in this chapter.
The method of data collection: the interview approach

The interview as a research tool “allows entrance into another’s person world and is an excellent source of data” (Speziale & Carpenter, 2007, p.95). For this study I used a semi-structured interview which is the main type of data collection in IPA. In this type of interview I had a set of questions which were only used as a point of reference to guide me as a researcher (Smith & Eatough, 2007). This enabled me to ask further questions to understand better the participants’ experience as well as to ask for clarifications when necessary to ensure that their accounts were properly understood.

The interview guide (Appendix A) was prepared in light of the literature review and was constructed as outlined by Smith and Eatough (2007). All questions were constructed according to the research question. This was done cautiously to ensure that the questions were open-ended and not in any way explicit. This was done to encourage participants to talk freely about their experience, with little prompting as much as possible (Smith & Eatough, 2007).

The interview questions focused on their experience, their quality of life and ways of coping. However it was not based solely on these. Questions about their beliefs, attitudes, perceptions and feelings were also taken into consideration. Additionally, field notes were taken to record any non-verbal cues and attention was made whilst listening to the participants, for any differences in their tone of voice. This was done to capture a holistic picture and understand better their experience and feelings about what was being narrated.

The interviews were conducted over a span of two months. They took place at the participants’ homes or at their relative’s place of institution. Each interview lasted approximately seventy minutes, allowing the participant to give as much detail as possible. The interviews were
carried out in Maltese since all the participants felt more comfortable to narrate in this language. The audio-recorded interviews were transcribed verbatim in Maltese. The only parts which are translated in English are those found in the write-up. These translations were done with the help of a linguist, to ensure an accurate representation of the participants’ accounts.

To help improve my interview questions, the first interview which I conducted was considered to be the pilot interview (Creswell, 2007). No significant changes were done to the main questions and hence this interview was also used in the analysis. However, I did improve my interview guide in terms of the language used because I noticed that certain questions were not properly understood.

**Ethical considerations**

As a researcher, it was my responsibility to employ all possible measures to ensure that no harm was done to the participants. In fact, before the start of this research, approval was obtained from the University Research Ethics Committee (UREC) and the “Malta Dementia Society” to ensure that all ethical issues were appropriately addressed (Appendix B).

An informed consent was obtained. I informed the participants about the nature of the research and that everything said was going to be used only for academic purposes. They were also assured that information collected will be held with strict confidentiality. To preserve the anonymity of each participant I used fictitious names and I changed or omitted any personal information which might disclose their identity.

Information about how the interview data was going to be collected and used was also provided. The participants were informed that the study was entirely voluntary and that they were free to withdraw from the interview without the need to provide a reason. They also had the
choice not to answer any questions which they did not want to answer. They were reminded that they had the right to access, rectify and erase data concerning themselves. The above ethical considerations were explained in the information sheet (Appendix C) and consent form (Appendix D).

I was aware that talking about a close relative with dementia could cause emotional distress. Therefore, safeguards to minimise the risks were given a lot of importance. Throughout the interview I applied several communication skills learnt throughout the psychology course to help the participants feel more at ease in narrating their experience. After the interview I asked the participants how they felt talking about their experience and whether there were any instances in which they relived distress. All of them expressed that they felt comfortable talking about their experience and felt that this can be used to help others who are in the same situation.

**Analysis of data**

The interviews were analysed as described by Smith, Flower and Larkin (2009). The analysis was carried out in an idiographic way where I analysed each interview individually before performing a cross-case analysis of the shared themes (Smith et al., 2009). This was done to aid the analytic process of “moving from the particular to the shared and from the descriptive to the interpretative” (p.79).

The first step of the analysis involved reading the first transcript for several times. This was done to become familiar with the transcript and with the participant way of thinking about the experience. The reading process was supplemented by listening to the participants’ voice and the flow of the interview. During this process I used the left hand side of the margin to write exploratory comments. Through my initial noting I focused on the descriptive component of the
experience together with the meaning of the experience for the participants. The exploratory comments were transformed into emergent themes and were written on the right hand side of the margin (Smith et al., 2009). An excerpt from an analysed transcript is presented in Appendix E.

After establishing a set of themes, I listed them in a chronological order. Emergent themes that linked with each other, were grouped together to develop a cluster of related themes (Smith et al., 2009). These clusters of related themes formed the sub-ordinate themes and were incorporated within a super-ordinate theme.

This process of analysis was repeated for the other transcripts. To allow new themes to emerge from each transcript, I tried to set aside any ideas which emerged during the analysis of the previous interviews as much as possible. By looking for patterns across cases, I integrated the findings from different transcripts and produced a master table of themes, which will be presented in the results chapter (Smith et al., 2009).

**Reflexivity: the researcher’s experience**

According to Creswell (2007) “how we write is a reflection of our own interpretation based on the cultural, social, gender, class and personal politics that we bring to research” (p.179). Hence, as a researcher I needed to examine my biases and assumptions related to the research to increase the transparency of my findings (Speziale & Carpenter, 2007).

In the introductory chapter I outlined my rationale behind my choice of study. The first includes the curiosity behind caregiving for a relative with dementia and the second is my own personal experience with family caregiving. I used to take care of my father, whom due to an operation had to stay in bed for several months. My father is an active and hardworking person, so it was difficult for me to see him constrained in a bed. The memory of this experience is still
unpleasant as I remember the frustration I felt during these months. This experience has made me realise the efforts made by caregivers who pursue this role for an indefinite period of time such as in the case of dementia caregivers.

Through self-reflection, I was aware of the biases derived from my caregiving experience and this helped me suspend my beliefs and understand better my participants from their internal frame of reference.

**Rigour of the study**

First, I clarified any self-biases that I had, in order to minimise the influence of my approach taken on this research (Creswell, 2007). To further enhance the credibility of my research and eliminate some of my subjectivity, I requested a peer-review. Two of my colleagues examined the data and findings. I then checked my interpretations with that of the reviewers and my analysis was consistent with theirs.

Since the participants are the experts in their own experience, I utilised another validation technique proposed by Creswell (2007), that of respondent validation. A letter (Appendix F) with the preliminary analysis of their interview was sent to some of the participants. Through this I confirmed that the data gathered was eligible to be used in my research and that it is an accurate representation of their beliefs.

**Conclusion**

Having provided detailed information on how the research was carried out, I have established that this process has given me insight into the caregivers’ experience. I think that by taking into consideration ethical criteria, the participants were able to feel more comfortable in sharing their
experience as truthfully as possible thus compiling data which is more credible. In the next chapter, I will be presenting the findings.
Chapter 4

Presentation of findings

Introduction

In this chapter I will present the participants’ profiles and the results obtained from the six semi-structured interviews. Each theme will be supported by excerpts in order to elucidate this experience as much as possible.

Participants’ profile

An overview of the participants’ profiles is presented in a table. To safeguard the identity of each participant I used fictitious names and any information that might disclose the person’s identity was omitted or changed (see table 1).

The themes

From the analysis of the six interviews, four super-ordinate themes emerged (a) ‘Embarking on a new, life-changing experience’ (b) ‘Confronting the changes and consequences’ (c) ‘Taking control of the situation’ and (d) ‘Identifying positive aspects of caregiving’. Sub-ordinate themes are nested within these themes to narrate the experience of the caregivers. The themes are in sequence to convey the passage of time as dementia progresses (see table 2).
<table>
<thead>
<tr>
<th>Fictitious name</th>
<th>Helen</th>
<th>Julia</th>
<th>Steve</th>
<th>Lydia</th>
<th>Andrew</th>
<th>Lisa</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Familial relationship</strong></td>
<td>Wife</td>
<td>Daughter</td>
<td>Husband</td>
<td>Daughter</td>
<td>Son</td>
<td>Daughter</td>
</tr>
<tr>
<td><strong>Age of carer</strong> (approx. years)</td>
<td>70</td>
<td>55</td>
<td>65</td>
<td>65</td>
<td>50</td>
<td>60</td>
</tr>
<tr>
<td><strong>Age of relative</strong> (approx. years)</td>
<td>70</td>
<td>80</td>
<td>65</td>
<td>90</td>
<td>80</td>
<td>80</td>
</tr>
<tr>
<td><strong>Duration of care</strong> (approx. years)</td>
<td>10-12</td>
<td>10-12</td>
<td>8-10</td>
<td>6-8</td>
<td>6-8</td>
<td>8-10</td>
</tr>
<tr>
<td><strong>Participant’s Profile</strong></td>
<td>She is a widow and feels regret that she was not present when her husband passed away. She tried to keep things as normal as much as possible. She found a lot of cooperation from her family.</td>
<td>Single Her experience is one of suffering. Feels lonely and isolated from her family and friends. Did several arrangements to take care of her mother.</td>
<td>He lives life day by day with a positive outlook towards life. Love has been his driving force that helped him surpass the difficulties encountered. He provides what’s best for his wife without taking himself into consideration.</td>
<td>Single Finds a lot of cooperation from her family. She feels guilty because she had to institutionalise her mother against her will due to her mother’s own health reasons.</td>
<td>Only child He found a lot of cooperation from his wife. He keeps himself informed about dementia care and applies this knowledge to assist his mother. Given the circumstances, he had to institutionalise her.</td>
<td>Single She did not find any cooperation. Having a full time job she had to institutionalise her. Even though her mother was institutionalised she assisted her continuously. Being a health care professional she applied her work skills to provide the best care.</td>
</tr>
</tbody>
</table>
Table 2: Master table of themes

<table>
<thead>
<tr>
<th>Super-ordinate theme 1:</th>
<th>Embarking on a new, life-changing experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Becoming aware of memory loss, unusual behaviour and changes in personality</td>
<td></td>
</tr>
<tr>
<td>1.2 Taking the role of a caregiver</td>
<td></td>
</tr>
<tr>
<td>1.3 Becoming immersed in the caregiving role</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Super-ordinate theme 2:</th>
<th>Confronting the changes and consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Experiencing a downfall in personal health</td>
<td></td>
</tr>
<tr>
<td>2.2 Sacrificing one’s social life</td>
<td></td>
</tr>
<tr>
<td>2.3 Perceiving the relative as a child and oneself as a parent</td>
<td></td>
</tr>
<tr>
<td>2.4 Grieving the losses brought about by dementia</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Super-ordinate theme 3:</th>
<th>Taking control of the situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Dealing with the behavioural and psychological manifestation of dementia</td>
<td></td>
</tr>
<tr>
<td>3.2 Juggling caregiving demands and personal life</td>
<td></td>
</tr>
<tr>
<td>3.3 Reaching out for help</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Super-ordinate theme 4:</th>
<th>Identifying positive aspects of caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Experiencing personal growth and development</td>
<td></td>
</tr>
<tr>
<td>4.2 Growing a sense of appreciation towards one’s relative</td>
<td></td>
</tr>
<tr>
<td>4.3 Deriving satisfaction from being a caregiver</td>
<td></td>
</tr>
</tbody>
</table>
Super-ordinate theme 1: Embarking on a new, life-changing experience

All caregivers described this circumstance as a new experience which changed and turned their life upside down. They recalled the first signs of dementia as being very striking and express an overwhelming feeling of uncertainty since they could not identify what was happening to their relative. When their relative got diagnosed, the participants had to decide whether or not to pursue this role. Several factors aided their decision. As time passed, the caregivers got more immersed and over-involved with their role.

1.1: Becoming aware of memory loss, unusual behaviour and changes in personality

Through the initial symptoms of dementia, caregivers were uncertain of what was happening to their relative. They witnessed their relative behaving in a way which was unusual to them. Some took this lighter than others as they did not think their relative’s changes were something serious: “initially you wouldn’t put it [dementia] down as being a condition; you would just say it is a one-off” (Helen). Others panicked and experienced constant worry. Lydia explained that she became aware of her mother’s memory loss during a vacation they took together. Her mother was unable to recognise her for two and a half days: “I went berserk! She [mother] kept saying ‘I want Lydia’, I told her ‘I’m Lydia.’ I realised that [she] wasn’t trusting and recognising me.”

Participants also witnessed changes in their relative’s personality and behaviour. They explained several instances where their relative started to use foul language; became aggressive and started to fear almost everything. Steve narrates that his wife used to put his clothes in the kitchen cupboard instead of the closet. These changes made them seek medical attention.
When the doctor told them the diagnosis, they felt shocked and found it difficult at first to accept it. Helen expressed that dementia was the last thing she expected her husband (John) to have:

[The doctor] had told me ‘I came to visit you more than once, I also came several times for your children but I’ve never came for John!’ His [John] brothers’ suffer from heart disease; I used to expect it without saying it and then he had to suffer from dementia?! I had never thought of it.

Lydia also found it very difficult to accept the diagnosis and it took her quite a long time to come to terms with it. She explained that after many years, her sister is still in denial:

[When the doctor told me she has dementia] we [family] couldn’t acknowledge it. You sort of fight off the situation and start saying to yourself ‘It’s not true.’ In fact my sister [is still in denial] up to this very day.

Contrary to this, Julia explained that she will never accept her mother’s condition and if by some miracle she could cure her, she would:

And then I realised and came to the conclusion, I’ll never accept it [dementia]. It’s an illusion to say ‘I accept it’. If I could, I would change her [mother]. I accept it and I live with it but if I could change [it] I would.” (Julia)

1.2: Taking the role of a caregiver

When the diagnosis was made, the participants had to decide whether to be a caregiver or not. Their decision was influenced by the doctor who made the diagnosis, extended family members and friends.
Some caregivers expressed that the doctors encouraged them to institutionalise their relative. Lisa described that the way the doctor suggested it, was disrespectful: “she [mother] has dementia, she is not fit to stay home, have you thought of an institution?” On the other hand, Andrew’s doctor did not want him to institutionalise his mother because she was still in the moderate stage of dementia. He explained that “I used to go against him [doctor] and tell him ‘you don’t know. We had been going through a rough patch lately.’”

Extended family members and friends also influenced the caregiver’s decision. Caregivers felt that having supportive family and friends could help them keep their relative at home. Helen described that if her children had not been willing enough to help her, she would not have been able to keep her husband at home.

Ultimately, the decision was the responsibility of the caregivers to make: “I [emphasis] had to decide what’s going to happen...nobody gets into it [caregiving] with eyes wide open” (Julia). Several reasons determined why they took this role. However, the main reasons revolved around the fact that family comes first and due to their unconditional love towards their relative:

Unless you do it [caregiving] out of love you wouldn’t do it. I do it and keep on doing it because I do it with great love. I’m ready to give my life for [her] and I say it with tears in my eyes [crying]. (Julia)

Another reason was family loyalty. Caregivers felt a sense of obligation, commitment and duty towards their relative. Being an only child, Andrew felt obliged to take care of his mother: “after all she’s my mother, if the person is a relative you don’t have another choice other than helping them.” Steve also expressed a sense of commitment in living up to the marital vows: “If
you’ve spent thirty years, forty years, twenty years with someone, you’re not going to get rid of them in a split of a second.”

Caregivers also felt that caregiving was a chance for them to reciprocate the care given by their relative. Julia described that now it is the time to repay her mother for all her nurturance.

1.3: Becoming immersed into the caregiving role

As time passed, caregivers became immersed and over-involved with the caregiving role as dementia became part of their life. As a result, they ended up caring too much for their relative’s well-being most often at their own expense: “you stop caring about yourself” (Helen). Caregivers also explained that they had to sort their life priorities. Julia explained that even though the pain was unbearable, she postponed her Carpal Tunnel’s operation to cater for her mother. In a nutshell, caregivers ended up without a life of their own:

Don’t we have our own lives to live? I’d have preferred a life in jail as I would have grabbed several books, go in the yard, meet others and talk to them [...] I would have been able to do what I wanted [...] but in this situation I can’t do anything [emphasis]. (Steve)

Caregivers admitted that as dementia progressed, the frequency of providing care increased. Care was provided continuously and on a daily basis. The feelings of sadness, frustration and stress were apparent throughout the whole experience. In fact, caregivers felt that this experience was very overwhelming: “you can’t stop otherwise if I had to stop I would end up sprawled on a chair and never get up” (Julia). When caregivers realised that they reached their limits in compensating for their relative’s illness, feelings of anger, helplessness and fear emerged.
Lydia expressed that she was becoming very irritable and angry, due to the lack of energy she had. Despite all this, when her mother had to go to hospital she did not want to take her, fearing that the health care professionals might refer her mother for institutionalisation. Andrew described how helpless he felt when his mother was not feeling well and he had no idea what to do. On the other hand, Julia expressed that her worst fear is that of getting ill.

Being immersed in such a role, caregivers experienced a feeling of burden. Andrew explained caregiving “is like having another part-time job in addition to your full-time job...a burden.” Having the full responsibility of someone who is not psychologically present posed a great toll on the caregivers. They had to make a lot of decisions for their relative who was unable to make any choices. Overall, caregivers experienced “a huge strain” (Lisa). In fact, Julia described that because of the burdens of work and caregiving, she momentarily experienced burnout:

I got burnt out...I was constantly feeling anxious going to work...in addition to coming back home and seeing her [mother] so aggressive. I was falling apart [...] At work I had to deal with difficult situations. And then I get home and find the same situation twenty-four hours.

Some caregivers, especially those who were retired, mentioned that financial problems posed an additional burden. Although, dementia is incurable, caregivers still opted to buy the medications needed to prolong the condition. Apart from the medications, caregivers needed to sustain the household, pay additional assistance (e.g. helpers) and other health services:

[For the medications] you’ve got almost fifty euro every fortnight. That’s hundred euro in a month, you have eleven euro [for the pills] of osteoporosis. Tell me! How is all this possible from a miserly pension? (Steve)
Super-ordinate theme 2: Confronting the changes and consequences

Being so immersed in such a role, resulted in a downfall in the caregivers overall QoL. As dementia progressed and their relative became more dependent, caregivers witnessed relationship deterioration and perceived a shift in their role. These represent several kinds of losses. However, caregivers mostly grieved the psychological loss of the person they once knew.

2.1: Experiencing a downfall in personal health

Caregivers experienced a downfall in their psychological and physical health. They described instances of mental exhaustion, sleep deprivation and physical strain.

The participants expressed that this situation was mentally exhausting because of constant worry which did not decrease even if their relative was institutionalised. Andrew explained that having one’s mind always on the go, interfered with several other aspects of his life: “if I go out, without even knowing I start talking about it [dementia].” Lydia described she had the beginning of a depression: “you’ll be overtired and you won’t even realise what kind of depression you’re getting in. I had the beginning of a depression without realising."

Moreover, having to provide constant care even at night resulted in sleep deprivation. To cater for her mother, Lydia explained that her “night span involved sleeping for an hour and a half, waking up and going back to sleep.” Caregivers expressed that they spent entire nights awake and when they slept they did this with one eye open.

The participants also experienced substantial amount of physical strain. Steve admitted that he feels dead tired. Physical strain arose from the fact that they had to lift up their relative to assist them in tasks of daily living (e.g. bathing and putting them to sleep). This was very challenging.
Helen described her feeling in lifting up her husband: “when you place him [husband] in bed he is like an object...dead. I wasn’t able to roll him on my own.” Julia also expressed that since her mother suffered from incontinence; she had to wake up at night to change her mother’s clothes and the bed sheets. This made her feel very angry.

### 2.2: Sacrificing one’s social life

All caregivers indicated that with caregiving “your life completely ends” (Steve). As a consequence they became socially withdrawn. Some caregivers experienced this out of their own will because they felt it was unjust to continue with their social life. Whilst others, even though they wished their social life was still intact couldn’t because no one offered support, and family and friends isolated them. The former was apparent in Helen’s experience where she indicated that even though others encouraged her to go out and have a rest; she did not want to:

> I was one of those who used to attend coffee morning...everything ended. My children used to tell me ‘Mum, go!’ [I used to tell them] ‘No, I don’t feel like it’ [...] The doctor used to ask me ‘do you want to rest for a few days?’ I would tell him ‘I won’t rest, it will be worse because I would want to see him [husband].

Apart from becoming socially withdrawn, caregivers indicated that through this experience they also experienced a loss of leisure, deprived from doing the things they loved. This further hindered their opportunity to socialise with other people. Lisa described that:

> Before [caregiving] I used to go to work, come back home and find my mum doing all the house chores! I used to go out [...] go on vacations three times a year. However, in those ten years I never [emphasis] went anywhere!
2.3: Perceiving the relative as a child and oneself as a parent

All caregivers compared their relative’s behaviour to that of a child and themselves as the parent who needs to supervise and provide care continuously. This brought about a shift or change from their usual role, depending on whether they were the spouse or child of the relative with dementia.

Steve felt that his wife became like a toddler who just learnt how to walk. Consequently he couldn’t trust her around the house. In fact he had to sell their big house and find a small apartment so he could supervise her and ease off his mind:

It’s like having a toddler who has just learnt how to walk. You have to be on the lookout whether she [wife] is going to fall down the stairs or climb there [pointing]. It’s the same exactly! Compare them with a boy or girl who has just learnt to walk.

Andrew and Julia, the child of the relative with dementia, admitted that they felt a role reversal. This role was something new for them as they were the one’s dependent on their mothers before dementia not the other way round. As Julia described “the roles changed, whereas before she [mother] was the carer and I the child...everything changed.”

2.4: Grieving the losses brought about by dementia

All caregivers experienced suffering and grief for the loss of the person they once knew, yet still alive. They also witnessed a deterioration of their relationship with their relative. This brought about the grief of interacting with someone who’s not psychologically present. Ultimately, caregivers had to come to terms that “every phase of this condition [is a loss], the more it progresses...it will kill her [mother] eventually” (Julia).
Julia explained that she talked to her mother without realising that “you are reasoning with a person who is fully there, but who [is] not fully there.” She explained an ongoing heartache in having to remind her mother that she is her daughter. Part of her still hopes she will remember:

> When I do it [trying to remind her mother that she is her daughter], I leave everything and go smoke a cigarette. I have her memories; she was so strong and so caring. That is, you know your mother how she normally is and now you are seeing your mother in this state.

In Lisa’s experience it is apparent that she also grieved the relationship she once had with her mother (Christa). Christa’s last memories were when Lisa had a car accident and was convinced her daughter died. Hence, Christa never recognised Lisa as her daughter. Consequently, Lisa felt heartbroken and doubtful.

> Do you know what passes through my mind when my mum doesn’t recognise me? ‘I am sure she didn’t love me.’ She [mother] used to tell me ‘I had a daughter, but she was run over by a car.’ That’s what she remembers. For her I was always a sister...

**Super-ordinate theme 3: Taking control of the situation**

Caregivers indicated that they found different ways to cope with the situation. To ease off their minds, caregivers did several things to deal with the behavioural and psychological manifestations of dementia. Moreover, being immersed in such a role they had to juggle between the demands of caregiving and their personal lifes. When the demands of caregiving increased, they had to find support.
3.1: Dealing with the behavioural and psychological manifestations of dementia

Participants inferred that dementia is very unpredictable. Consequently, caregivers were living in constant fear that their relative would be in danger. Lydia also explained that “as a carer I couldn’t trust her with anything...couldn’t trust her for one second, otherwise you’ve had it!” Hence, they took several precautions to cater for their relative’s safety and put their minds at rest. For instance, some caregivers expressed that they got rid of any electric appliances that might be dangerous to their relative.

Another difficulty was the fact that their relatives used to wander a lot around the house. This created a problem especially for those caregivers who lived in a big house. Apart from wandering around the house, caregivers expressed that their relatives attempted to go outside the house several times, especially at night. As a precaution, Andrew explained that he installed a door alarm, so that if his mother opens the door, his phone rings. Similarly, Helen described that;

I became frightened [with] the car! Once, he [husband] went to visit my sister and told her, ‘you know what I’m going to do? I’m going to throw myself into the sea.’ That’s when we decided to lock the interior door [...] and I took his keys as he was even starting to go out at ten at night.

Caregivers also had to deal with the psychological manifestations of dementia. They indicated that their relative was unable to differentiate between what’s real or not. Steve described that he had to get rid of all the mirrors at home because “as soon she [wife] spots a mirror she thinks there is another woman in the house... she becomes really aggressive and starts calling me names left, right and centre.” Similarly, Julia described that her mother is convinced that television presenters are seeing her:
Recently, she was straightening her blouse and told me, ‘shhh, they [TV presenters] are watching us.’ The fact that I sometimes get angry with her, helps. So sometimes when you get angry [she] shows some kind of improvement.

3.2: Juggling caregiving demands and personal life

With an increase in caregiving demands, caregivers found it difficult to balance the responsibilities of their role with their personal life. Despite this, they reported that they have learnt along the way to “work around the clock” (Steve). Julia described her normal routine:

For instance, if on Mondays I am off, I spend the morning here at home doing house chores...but then in the afternoon I pay the helpers from two till six o’clock in order to go out for a bit...otherwise I’d never leave the house.

Those caregivers who had a job found it more difficult to cope with their routine. Some did several arrangements at work whilst others had to quit their jobs such as in the case of Steve. Lydia explained she reached an agreement with her employer to start working from home: “I used to put her [mother] to sleep at ten o’clock or keep her by my side and start working at ten o’clock. There were times where I kept working till one in the morning.”

3.3: Reaching out for help

Although caregivers did their utmost to care for their relative alone, there came a point where the demands of caregiving increased so much that they had to reach out for help. Caregivers identified different kinds of support. These are; day care centres, helpers, friends, the “Malta Dementia Society”, extended family members, doctors, work and institutions. These provided a sense of reassurance. For example, Lydia explained that:
She [friend] told me ‘don’t make a mountain out of a molehill, God won’t give you more than you can handle’ and it was true that gave me peace of mind. I was still in that situation which got worse but that calmed me down.

Moreover, caregivers expressed that they found courage to face this hard situation by turning towards God: “I used to pray to God ‘God allow me to keep caring for my mum’” (Lisa).

Support made a difference on how they coped with this situation and through this they felt more relieved and at rest. Steve acknowledged that if it wasn’t for the institution he would not be able to cope. Reaching out for help meant that caregivers accepted the fact that it’s fine if they cannot do everything on their own: “if as a carer you find yourself saying, ‘this is the end, I can’t go on’...it’s OK you are only human...no need to pressure yourself!” (Julia).

**Super-ordinate theme 4: Identifying positive aspects of caregiving**

Although this experience is very hard to endure, caregivers identified several positive aspects of caregiving. They grew and learnt from this experience. They gained a greater depth of appreciation for what their relative represented prior to dementia. They also reported a sense of satisfaction in fulfilling such an important role and in seeing the whole family more united through this life adversity.

**4.1: Experiencing personal growth and development**

Caregivers mentioned that overall they have matured in several ways through this experience. They indicated that they increased interest and understanding of dementia and also learnt new skills. Some caregivers also expressed that through this experience they have also developed in their faith. Julia expressed that faith has given her strength to see the positive
aspects in life: “I also grew in the way I see life. I grew a lot in faith and I also learnt to let go. That’s what faith is for me. You have to trust in God.”

Moreover, through this experience caregivers have improved in their patience, as through the progression of dementia, they started to interact more patiently with their relative. Steve stated: “[the other caregivers] have to be prepared for everything and they need to have patience, I am short-tempered however I try my best to back down.”

4.2: Growing a sense of appreciation towards one’s relative

Through this experience caregivers grew a sense of appreciation towards what their relative represented. Some expressed verbally an immense gratitude towards things that their relative did for them but most often took for granted. Others talked about their relative with great fondness whilst recalling how their relative was prior to dementia.

Steve recalled that through this difficult experience he grew a greater respect for what his wife represented. He shared with me what a dedicated wife she was, what a good cook she was and how many times she sewed him clothes. Steve described his wife as being “a real woman.” He also indicated that through their forty years of marriage they cherished together both the good and the bad times. Furthermore he stated that his wife has given him the best gift in life by giving birth to his children:

I learnt a lot that when things like these happen...I grew more respect for that particular person. You have to bear in mind those forty years you spent with that person...for example if you’ve suffered, she [wife] suffered as well, if she gave birth to your children she gave you the best gift in life.
Lisa felt guilty that when her mother was still alive she constantly fought with her. This has been bothering her over the years and she sought reassurance from her friends who reminded her that the most important thing was that when her mother needed her, she was always present. She indicated an appreciation of all the things her mother did for her but she took for granted: “I used to fight a lot [with her], I don’t know about what...nonsense [...]. She did a lot of things for me and she loved me but I... [heartbroken].”

Julia expressed that through this experience she realised what an important role her mother has in the home and family. She stated that when she returned home after taking her mother to hospital the house was empty. With tears in her eyes she articulated that since she has no family of her own, she has grown up with her mother. As a woman she understands all her mother’s sorrows and appreciates how much of an effort her mother did to keep her family united;

“Now I know...there I become emotional [crying]...Now I know how much she [mother] suffered for us and loved us. I grew up with her and became a woman and as a woman I understand her sorrows...How much she suffered in silence so as not to cause arguments [...] she was always caring, always loving.

4.3: Deriving a sense of satisfaction from the experience

Caregivers identified several aspects of this experience in which they derived a sense of satisfaction. All caregivers expressed satisfaction in being always present to provide their relative with the best care. Some caregivers expressed that they felt mostly satisfied in assisting their relative in activities of daily living and in having recognition from other family members for doing a good job. Whilst, others reported that they were satisfied in having such a united and supportive family.
Lisa admitted that she felt satisfied from the fact that she was the only one capable to take care of her mother. As a healthcare professional, she was satisfied in being able to apply the skills acquired from her job to assist her mother as best as she could: “I used to feel very satisfied, I used to do everything for her, I loved it, it’s like ‘Yes! I am the one who took care of her!”

Moreover, Lisa expressed a sense of satisfaction in knowing that her family recognised her efforts in providing the best care. In fact, her cousin acknowledged Lisa’s efforts and expressed that without Lisa, her aunt (Rita) would have died long time ago.

When my mother died, my cousin told them [family]; ‘She [Lisa] gave her [Rita] all the care [...] It’s because of Lisa that aunty stayed alive. If it wasn’t for Lisa, aunty Rita would have been long gone.

On the other hand, Lydia and Helen expressed that during this time they felt satisfied in having an understanding and supportive family. With a positive note, Helen explained that her husband was very much loved by the family and during this time all the family had come to see him.

Conclusion

In this chapter I presented the findings extrapolated from the analysis of the six interviews. In the following chapter, I will discuss these results in light of the literature review presented in chapter 2.
Chapter 5
Discussion of Findings

Introduction

In this chapter I will discuss the findings obtained from the semi-structured interviews. These will be compared and contrasted with the reviewed literature presented in chapter 2.

Discussion of findings

Based on the theoretical model of Pearlin et al. (1990) as cited in Iecovich (2008) the aim of this study was to take an eclectic approach towards the caregiving experience. As my findings suggest, this experience is multidimensional. I decided to present the results in sequence to capture a snapshot of this experience and convey the passage of time as dementia progresses. Even though the study of Cilia Custo’ (2012) focus on informal caregiving with relevance to bedridden patients, my findings and hers are similar in the way we perceived such a situation. I think the gist of the family caregivers experience is similar, regardless of the type of condition. The distinctive characteristics of each condition are what make our results different. For instance, dealing with the unpredictability of dementia is different than having a bedridden elderly.

Though participants reported somewhat similar experience, it is apparent that there are differences in how each caregiver perceived this experience. As Lazarus and Folkman (1984) indicate, different individuals cope differently through the same life adversity. I think the way they perceived such a situation, was also influenced by the type of relationship they had with the care-recipient and their contextual background, such as education and socio-economic status as well as amount of support received.
Embarking on a new, life-changing experience

As Butcher et al. (2001) suggest caregivers described this novel experience as life-changing. This theme explored how caregivers became aware of their relative’s dementia, the several factors that motivated them to pursue this role and the effects this role had when caregivers became immersed with their relative’s care.

The findings indicate that at first caregivers experienced a feeling of uncertainty which over time manifested itself into constant worry. This made them seek medical attention. The caregivers expressed that when the doctors told them the diagnosis they felt shocked and in denial. These findings are consistent with Pfeiffer (1999), Willoughby and Keating (1991) and Kuhn (1998). Contrary to what Dupius et al. (2004) and Grollman and Kosik (1996) indicate, participants did not struggle to get a diagnosis and when this happened they did not express a feeling of relief. The findings challenge these perspectives as participants report that the doctors promptly identified the problem and gave them the correct diagnosis, hence indicating a good medical support for patients with dementia. However, despite the ease of finding an accurate diagnosis, my results confirm Dupius et al. (2004) findings that this situation is still very hard to accept, with some of the participants never coming to terms with it.

Although the decision to take up this role was solely of the participants, some caregivers expressed that extended family members influenced their decision. This is because as Tabone (1995) indicates the Maltese family is characterised by a high level of unity where families tend to share everything. The caregiver’s decision to pursue this role was also influenced by doctors and friends. As Cilia Custo’ (2012) indicates some participants expressed that the doctors either encouraged or discouraged them to take up this role. I think that Maltese families tend to
perceive their doctor and friends as part of their family system. Hence, this situation becomes an issue for all those who have a direct contact with and makes part of the caregiver’s network.

The participants felt that taking care of their relative is an obligation, a commitment and a duty. Spousal caregivers expressed a sense of duty and commitment in living up to the marital vows. This echoes findings from previous research (Triosi & Formosa, 2006; Innes et al., 2011; Aneshensel et al., 1995). Catholic values around commitment in marriage are still very strong (Triosi & Formosa, 2006) and caregivers felt it was their responsibility to abide by them.

Another reason that motivated them to take up this role was reciprocity of care. Caregivers appraised this situation as an opportunity to reciprocate all the nurturance their relative had given them. This is consistent with the studies done by D’Amato (1995) and Willoughby and Keating (1991). The results also suggest that caregivers decided to take up this role out of love. This was considered also as the main driving force that helped them keep on going, similar to the findings by Kaufman et al. (2010). I think love can help the caregivers deal more positively with the situation. As participants inferred, love also determines the type of sacrifices caregivers are willing to engage in to provide their relative with the best possible care.

Dementia becomes part of the caregiver’s life. As Austrom and Hendrie (1990) indicate, caregivers started to perceive this role as part of their identity. The results indicate that the frequency of providing care increased as the demands of caregiving also increased. As Triosi and Formosa (2006) suggest, caregivers ended up taking care of their frail elderly twenty-four hours a day.

My findings tally with Loukissa et al.’s (2009) findings that caregivers become so immersed in their role that they were willing to make any form of adjustment even at their own expense.
When caregiver’s efforts to compensate for their relative’s condition failed, feelings of anger, helplessness, sadness, stress, fear and frustration emerged. These emotions are consistent with Butcher et al. (2001) and Pfeiffer (1999). My results go a step further in explaining that these emotions arise because caregivers get over-involved with their relative’s care.

As outlined by Pierce et al. (1989) caregivers indicate a substantial amount of burden which does not decrease even if their relative is institutionalised. Participants expressed that they experienced mostly financial burden. This is at par with George and Gwyther (1986). This could be because, apart from the fact that dementia care is expensive, some of the participants were retired so they had to struggle to keep up with the expenses. Moreover, participants described having an additional burden of making decisions in the name of the relative. I think this posed a huge responsibility on the carers in making the right decision, in order to prevent feelings of guilt. Taken all together, the findings suggest that caregivers’ burden and over-involvement had a negative effect on the carer’s overall health and social life. This supports the findings of Iecovich (2008) and Ekwall (2004).

**Confronting the changes and consequences**

I believe that after being a caregiver for a long, the carers end up becoming the second victim of dementia. This theme captured the consequences that arise as a direct result of caregivers’ burden. The findings indicate that caregivers experienced a downfall in their personal health and social life. Furthermore it also tackled changes that caregivers encountered through the progression of dementia such as role reversal and grief.

As Triosi and Formosa (2006) argue, caregiving does not stop at night. My findings suggest that being constantly worried contributed to mental exhaustion and sleep deprivation. Similar to
Schulz and Beach (1999), some of the participants also experienced anxiety and depression, hence requiring medication. Acton (2002) suggest that caregivers practise less self-care behaviour. The participants’ accounts support this idea, as they expressed a feeling of reluctance to engage in self-care behaviour. In my opinion, caregivers become so over-involved with providing care that they prioritise the needs of their relative before their own. Apart from this, similar to the findings of Ory et al. (2000), caregivers also experienced several physical problems over the years because they had to lift their relative so frequently.

Caregiving had an impact on the carer’s social life, due to the amount of hours caregivers spent engaged in this role (Triosi & Formosa, 2006). I think that another reason why caregivers sacrificed their own social life is because they felt guilty in leaving their relative at home whilst they are out having fun. Others expressed that their family and friends isolated them. Dupius et al. (2004) describe that one possible reason that this happens is because neither family nor friends understand fully the condition of the caregiver’s relative. My results and Rogers (2001) agree that caregivers experienced a loss in their leisure activities which deprived them from the opportunity to socialise with others.

I think that caregivers also experienced deterioration in their relationship with the care-recipient. Similarly to what Cilia Custo’ (2012) highlights, the participants experienced role reversal and started to perceive their relative as a child. I think that since Maltese caregivers live at a close proximity to their relative, they have a greater chance of witnessing and experiencing such a role change, when compared to foreign countries.

Austrom and Hendrie (1990) argue that caregivers experience several kinds of losses along the progression of the condition. As already stated, participants experienced the loss of their
social life, a downfall in personal health and a loss of their usual role. These are consistent with what Holley and Mast (2010) refer to as secondary losses. However, the most remarkable loss that caregivers grieved was their relationship with the care-recipient and the relative’s personality.

**Taking control of the situation**

In this theme I delved into how caregivers coped with this situation. As Taylor (2009) suggests, caregivers took these measures in an effort to change the circumstance and make it more favourable.

The findings suggest that caregivers had to deal with the behavioural and psychological manifestations of dementia. I think that coping with these is a response towards eliminating some of the burden. Some caregivers also expressed that their relative was unable to differentiate between what’s real or not, which I think, further exacerbated the loss of their relative’s personality (Doka, 2010).

Caregivers also suggest that they had to juggle the demands of caregiving with their personal life. In fact, the participants expressed that they had to make several arrangements especially, those who had a job. As the National Alliance for Caregiving (2009) reports, some caregivers indicated changing the job conditions or else leaving work altogether. I think, employment can enhance the caregiver’s social life as it can serve as a distraction from their daily caregiving routine.

When caregivers became aware that they had their own limits, they reached out for help from various formal and informal supports. This is consistent with the study of Willoughby and
Keating (1991) and Pfeiffer (1999). I think that the short distances in Malta enable a greater chance of availability for social support when compared to foreign countries (Tabone, 1995).

**Identifying positive aspects of caregiving**

Even though this situation is very hard to endure (Butcher et al., 2001), this theme presented different positive aspects that caregivers derived from their role. I think that this aspect contributes to a more holistic understanding of the experience by looking at both sides of the coin. Moreover, I think that the positive outcomes play a major role in the caregivers’ overall well-being as these can eliminate some of the negative outcomes (Semiatin & O’Conner, 2004). From the interviews I noticed that caregivers struggled to reflect upon the positive outcomes. It might be because it is more difficult to identify positive aspects in the midst of a continuous suffering experience. Despite this, all of them inferred or identified at least one positive thing that emerged. This is consistent with Cohen et al. (2002).

Similar to the findings by Dupius et al. (2004) caregivers experienced maturation, an increased understanding of dementia, new skills and an increased patience. Dupius et al. (2004) also mentions that caregivers derive a sense of satisfaction in doing a good job. This is consistent with my participants’ experience.

Participants also mentioned that they increased in their faith. Religious values are deeply ingrained in the Maltese society and caregivers derive support from it (Tabone, 1995; Triosi & Formosa, 2006). In fact, similar to what research suggests, caregivers expressed that spirituality has been their source of strength and guidance (Stuckey & Gwyther, 2003; Snyder, 2003).

My findings suggest that caregivers also grew a greater appreciation towards what their relative did for them and what they represented prior to dementia which most often took for
granted. I think that the reason why caregivers experienced this is because they have never considered a life without their relative and the possibility of losing them.

**Conclusion**

This chapter discussed the findings obtained in light of the literature review. In the next chapter, I will be presenting the research salient findings, its strengths and limitations. Implications for future research and practice will also be discussed.
Chapter 6

Conclusion

Introduction

In this chapter I will outline the salient findings of my research together with its strengths and limitations. I will also present recommendations for future research and practice.

The research and its salient findings

The aim of this IPA was to elucidate the lived experience of caring for a relative with dementia. The focus was on how caregivers experience and perceive such a situation; how they cope with it and the impact it has on their QoL.

The findings suggest that the caregivers’ life changed from the moment their relative was diagnosed. Various reasons determined why caregivers decided to take up this role. As time passed, caregivers became immersed in their relative’s care even at their own expense. This resulted in several negative outcomes that affected their overall QoL. As dementia gradually progressed, caregivers experienced a shift/change in their role. Although, these imply several kinds of losses, caregivers grieved mostly the loss of their relative. Despite such difficulties caregivers managed to cope effectively and identified several positive aspects of caregiving.

Research contributions

The study sheds a light and elevates awareness on the experience of Maltese dementia family caregivers. At the same time, caregivers were also given the opportunity to voice and give meaning to their experience. Since in Malta research on family dementia care is scarce, I hope that these findings contribute to further knowledge in this area of study.
Research limitation

The main limitation of my research was the sample. Although great care was taken to ensure a fairly homogenous sample, this study did not take into consideration difference between male and female caregivers. Both spouses and children of a relative with dementia were included in this research; this means that the findings do not take into account the differences that exist between these relationships. Additionally, the study did not include a specific form of or stage in dementia. This is a limitation because different forms of dementia pose different demands on caregivers. Moreover, the demands of caregiving tend to increase as the relative progresses into the latest stage.

Another limitation arises from my own subjective biases and influences. Although I did my utmost to suspend them, I think it is impossible to completely eliminate and hence, I might have been unconsciously influenced or biased.

Implications for future research

This study has provided an in-depth understanding of the experience of dementia family caregivers. Given the complexity of this, I suggest several courses of action for future research that can aid to develop a more vivid picture of this experience.

Experiential studies on family caregiving might focus specifically on the difference between male and female caregiving as well as on the difference between caring for a spouse and for a parent. I also suggest that future research tackles dementia caregiving through a specific stage since through the latest stage, caregiving demands increase severely. Moreover, quantitative studies would also be significant to measure the outcomes related to caregiving. For instance, standardised tests could be used to measure caregivers’ burden, overall QoL and PAC.
**Recommendations for practice**

The findings of this research have a number of important implications for practice. It is evident that in Malta there is still lack of awareness about dementia. Participants expressed that there is a stigma about dementia which indirectly affects them. They add that since individuals with dementia are unique, there is the need for well trained professionals. Therefore, I think that the main pillar to increase awareness and educate professionals on how to deal with cases of dementia is education. A reasonable approach to this would be to develop initiatives where caregivers can share their knowledge about their own experience.

I think that professionals, especially psychologists could help the family deal with the initial shock of the diagnosis. Although there are several courses of action to take (e.g. institutionalisation and respite), most caregivers still opt to take care for their relative at home. Hence professionals can also assist, explain and prepare the caregivers for this challenging role.

As the findings suggest caregivers are at an increased risk of financial problems. One of the participants expressed the idea to develop a voluntary organisation where people can help caregivers by assisting their elderly relative. This would benefit caregivers in two ways. First, it will maximise the opportunity for the caregiver to have a rest from this role and secondly, it will decrease their financial burdens.

**Concluding note**

Overall, this experience of carrying out a research has given me the opportunity to apply the skills learnt throughout the psychology course into practice. This research has taught me the concept of caregiving; how to conduct a qualitative research; and how to tackle the different challenges that arise along the process. On a personal level, I have become more self-aware
regarding my presumptions. I have also learnt to be more considerate and emphatic. Most of all, from the caregivers’ heartbreaking experience, I learnt to appreciate my family even more.
References


Appendix A

Interview Guide

Demographic Data:

Age of caregiver:  
Relation to the care-recipient:  
Age of care-recipient:  
Duration of care:  
Frequency of providing care: 

Main Question

1. Can you please take me through your experience of being the main caregiver of your relative?

Other Questions

2. How did you decide that you were going to be the one to provide all the care?  
3. Can you take me through your typical day?  
4. What were the most difficult situations you faced while caring for your relative?  
5. How did your life change?  
6. How did the caregiving change over time?  
7. Did some aspects of caregiving become easier or more difficult?  
8. How do you juggle between your personal life and caregiving?  
9. Did you do make some arrangements (e.g. at work) to cater for your relative?  
10. How do you think this role affected you a) physically b) emotionally and c) mentally?  
   (Both positive and negative).  
11. What helps you keep on going on?  
12. Despite all the problems faced, are there any positive aspects of caregiving?  
13. Based on what you have seen so far with regards to caregiving, is there something you would like to share with caregivers who are just starting out their caregiving journey?  
14. What else needs to be provided, changed or improved in terms of support for caregivers in Malta?

Thanks for sharing this experience with me.

1. How did you feel speaking about your experience?  
2. Are there any other comments you would like to add?
Gwida għall-intervista

Informazzjoni demografika:

Eta’ tal- caregiver: X’tigi mill-qarib li tiehu hsieb:
Eta’ ta’ dak li qed tiehu hsieb: Ammont ta’ hin li tiehu hsiebu/ha:
Żmien li ilek tiehu hsiebu/ha:

Mistoqsija Prinċipali:

1. Tista’ tirrakuntali l-esperjenza tiegħek ta’ caregiving?

Mistoqsiijiet Ohra:

2. Kif iddeċidejt li inti ha tkun dik/dak li tiehu hsiebu/ha?
3. Tista’ tirrakuntali ġurnata tipika tiegħek?
4. X’kienu l-ikbar diffikultajiet li tiltaqa’ magħhom fl-irwol tiegħek?
5. B’liema mod inbidlet ħajtek?
6. Kif nbidel l-caregiving matul iż-żmien?
7. Kien hemm xi ċerti aspetti tal-caregiving li saru inqas jew iktar diffiċli matul iż-żmien?
8. Kif tqassam l-hin bejn il-hajja personali tiegħek u caregiving?
9. Kellhom isiru xi tibdillet (fix-xogħol ezempju,) biex tkun tista’ tlahhaq?
10. Kif affettwak dan l-irwol f’sens a) emożzjonali b) fiżiku u c) mentali? (fit-tajjeb u l-ħażin)
11. X’jghinek biex tkompli għaddej fil-hajja?
12. Minkejja l-problemi kollha li sibt quddiemek, tara li hemm affarijiet pożittivi fl-irwol tiegħek?
14. F’dak li ghandu x’jaqsam ma’ Malta u fejn ghandu x’jaqsam is-sapport mehtieγ ghalikhom, x’tahseb li hemm bżonn jigi provdut, jinbidel jew jimpruvja?

Grazzi ħafna talli qsamt miegħi din l-esperjenza.

1. Kif hassejtek inti u titkellem dwar l-esperjenza tiegħek?
2. Tixtieq izzid xi kummenti ohra ma dak li ghidna?
Appendix B:

Letter of Approval from the Malta Dementia Society

To whom it may concern

The Malta Dementia Society approves the research project “The lived experience of caring for a family member with dementia” by Ms. Deborah Spiteri under the supervision of Dr. Roberta Zahra de Domenico. Members of the society will be asked to participate on a voluntary basis to the study. Participants will remain anonymous and the researcher will not have any access to individual data and total confidentiality will be observed as requested by the Data Protection Act of Malta.

Sincerely,

[Signature]

Dr. Charles Scerri PhD
Secretary
Malta Dementia Society
Letter of Approval from UREC

To be completed by Faculty Research Ethics Committee
We have examined the above proposal and advise

Acceptance
Refusal
Conditional acceptance

For the following reason/s:

Signature: [Signature]
Date: 7 May 2012

To be completed by University Research Ethics Committee
We have examined the above proposal and grant

Acceptance
Refusal
Conditional acceptance

For the following reason/s:

Signature: [Signature]
Date: 1 June 2012
Appendix C

Information Letter

[Address]

Dear Sir/Madam,

I am a student at the University of Malta, currently reading for an undergraduate degree in psychology. In part-fulfilment of my course, I am carrying out a dissertation which explores the lived experience of people who are the main caregivers of a family member with dementia. The aim of this study is to find out and understand the carer’s feelings, attitudes and experiences.

My research will be carried out in a responsible manner with the help of my supervisor Ms. Roberta Zahra de Domenico, who shall assist and guide me through all the phases of my dissertation. Furthermore, this study was approved by the University of Malta Research Ethics Committee (UREC) where it ensured that all ethical issues were appropriately addressed.

I would like to carry an interview with you that will last approximately 1 hour. The interview will be held in a place that suits you. The data that is needed for this study is going to be collected through an audio recorder and is going to be governed by the Data Protection Act of Malta. The recorded interview will be transcribed and analysed in order to draw out themes. I will contact you personally after analysing the interview to ensure that my interpretation of your interview is an accurate representation of your experience. The final result will be made available through a talk in conjunction with The Malta Dementia Society at the end of the study. The recording will be used solely for academic reasons and kept in a safe place. After my graduation the recorded material will be destroyed.

Please note that participation in this study is entirely voluntary and you are free to withdraw participation. Should you agree to participate in this study, please be aware that all information that is collected will be held strictly confidential and your identity will not be disclosed at any point. Moreover, you have the right not to answer questions you would not like to answer, as well as to withdraw from the study at any time without the need to provide a reason for your withdrawal.

The Malta Dementia Society has sent this letter on my behalf in order to protect your contact details. Should you wish to participate in this interview or have any queries, please do not hesitate to call me on __________or contact me at __________.I would like to take the opportunity to thank you for your time.

Yours truly,

Deborah Spiteri
Ittra ta’ Informazzjoni

Għażiż sinjur/a,


Din ir-riċerka ha sseħħ b’mod responsabbli taht is-superviżjoni ta’ Ms. Roberta Zahra de Domenico, li ha tkun qed tmexxini u tghini f’kull fażi ta’ dan it-też. Barra minn hekk dan l-istudju ġie approvat mill- *University Research Ethics Committee (UREC)* fejn approvaw li kull fażi tat-teżi hija skond kif titlob l-etika.


Il-*Malta Dementia Society* bagħtet din l-ittra f’ismi biex tipproteġi l-identita’ u d-dettagli tal-kuntatti tiegħek. Jekk int tixtieq li tiipparteċipa f’din ir-ričerker jew għandek xi mistoqsijiet, hossok liberu/a li tikkuntattjani fuq dan in-numru __________ jew ibgħat e-mail fuq __________. Nixtieq niehu l-opportunita’ biex nirringrazzjaj tal-hin tiegħek.

Dejjem Tieghhek,

Deborah Spiteri
Appendix D

Consent form

Address:
Tel:
E-mail:

“The lived experience of caring for a family member with dementia”

I, the undersigned, am willing to participate in Deborah Spiteri’s research project entitled “The lived experience of caring for a family member with dementia”. I am aware that the interview will be recorded and that any relevant information shall be used solely for academic reasons. I understand that no personal information will be disclosed and that all information is anonymous. I understand that all recorded material will be destroyed after completion of the project. I understand that I have the right to access, rectify and erase data concerning me. I understand that I am allowed to withdraw from the project at any time and without having to provide a reason.

I have been briefed about the nature and the aims of the study, and have had the opportunity to ask further questions and seek clarifications. I am satisfied by these conditions and consent for participation in this study.

Participant’s Name: ............................
Participant’s Signature: .............................
Date: ..............................................

Interviewer’s Name: ..............................
Interviewer’s signature: .............................
Date: ..............................................

Supervisor’s Name: ..............................
Supervisor’s Signature: .............................
Dikjarazzjoni ta’ Kunsens għall-Intervista

Address:
Tel:
E-mail:

“L-esperjenza ta’ nies li jieħdu hsieb membru tal-familja bid-dimensja”


Isem tal-parteċipant: ......................................
Firma tal-parteċipant: ......................................
Data: .................................................

Isem l-intervistatur: ......................................
Firma tal-intervistatur: ......................................
Data: .................................................

Isem tas-superviżur: ......................................
Firma tas-superviżur: ......................................
## Appendix E

**Transcript Excerpt in Maltese**

**Table 3: The analysis of data**

<table>
<thead>
<tr>
<th>Exploratory Comments</th>
<th>Transcript in Maltese</th>
<th>Emergent themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>She started to realise something was not usual about her relative. She already suspected that her mother had dementia.</td>
<td>R: sibt id-dar dahna...l-borna inharqet umar jiftiha hu [hija]. Imbaghad ghidtilha [l-ommij] x’ghamilt u kwazi ma bdiex tiftakar x’ghamlet. Ghidt “eeee ġej l-inkwiet” jien, ghax ftit jew wisq tkun taf...</td>
<td>Emerging recognition unusual behaviour</td>
</tr>
<tr>
<td>Her relative changed a lot. She experienced a shift in her mother’s personality and attitude.</td>
<td>R: bil-kundizzjoni mhux l-ewwel darba id-dimenzja. Imma ma kienitx daqshekk komuni fhimt?</td>
<td>Changes in personality</td>
</tr>
<tr>
<td>Feeling that she lost her mother.</td>
<td>R: Ħafna, ħafna, ħafna, ħafna qed nghidlek l-behaviour taghha fejn qabel kienet doċli, helwa, tiċċajta u filli tghid “hallini tindahalx, hallini salvaġġa”...</td>
<td>Losing a person that she once knew</td>
</tr>
<tr>
<td>She cannot understand how her mother changed in this way.</td>
<td>R: li titkellem arroganti u titkellem tghajjat. Pjuttost jiena nghajjat jiġfieri. Jew</td>
<td>Questioning herself.</td>
</tr>
<tr>
<td>Her relative was never arrogant. Her mother</td>
<td></td>
<td>A shift in how her mother was and is.</td>
</tr>
<tr>
<td>English</td>
<td>Maltese</td>
<td>Italian</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>used to correct Julia’s behaviour in how to respond to her brother’s disability. However, with dementia she started to call her son ‘iblah.’</td>
<td>I-hija per eżempju jiena meta kont zgħira kont nghidlu “iblah”, għandu diżabilita’ intelletwali, kienet tghidli minn tant “iblah” tghidlu ...biex imbagħad bdiet tghidha hi!!! (enfażi) Heqqq... u ma baqghet tagħmel xejn, I mean, hekk jahasra kienet per eżempju tmur sal-knisja, nigi nsibha fis-sodda rieqda fil-hamsa, ghax hi tibda b’depression allura inti medication tkun ta’ depression sakemm jibdew... ghax there is a hairline difference bejn depression u bejn id-dimenzja...</td>
<td>Surprised and heartbroken</td>
</tr>
<tr>
<td>Julia felt surprised and heartbroken.</td>
<td>I: U żgur...</td>
<td>Encountering signs of dementia.</td>
</tr>
<tr>
<td>Encountering dementia problems.</td>
<td>R: U għal bidu tkun vera...uuu kienet jiġifieri tiggieled mieghi...tgholli idejha...nżommha lura fhimt? Allura anke jiena stess lanqas kont nkun naf kif ha nibihevja. Should I sort of be a little bit more fair and aggressive or should I be more gentle and kind? Illum l-ġurnata skoprejt li trid tkun gentle and kind even though she is aggressive. Imma bl-esperjenzi titghallimhom, wahdek...</td>
<td></td>
</tr>
<tr>
<td>Remembering how her mother was at first. She is very overwhelmed by her mother’s aggressive behaviour.</td>
<td>Lack of acceptance of mother’s behaviour.</td>
<td>Did not know how to tackle situation.</td>
</tr>
<tr>
<td>Did not know how to behave and respond to relative.</td>
<td></td>
<td>Learning as you go along.</td>
</tr>
<tr>
<td>Nowadays (after many years) she learnt to be patient and kind.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Transcript excerpt in English

<table>
<thead>
<tr>
<th>Exploratory Comments</th>
<th>Transcript in English</th>
<th>Emergent themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>She started to realize something was not usual from her relative. She already</td>
<td>R: I found the house full of smoke, the pot was burnt and he [brother] went to turn it off. And then I asked her [mother], ‘What did you do?’ but she could barely remember what she had done. I said to myself, ‘we’ve got trouble’, because in one way or another you would know...</td>
<td>Emerging recognition</td>
</tr>
<tr>
<td>suspected that her mother had dementia.</td>
<td>I: That’s right.</td>
<td>unusual behaviour</td>
</tr>
<tr>
<td>Her relative changed a lot. She experienced a shift in her mother’s personality and attitude.</td>
<td>R: ...about the condition. It’s not the first time dementia...However it wasn’t that common.</td>
<td>Changes in personality</td>
</tr>
<tr>
<td>Feeling that she lost her mother.</td>
<td>I: Exactly.</td>
<td>Losing a person that she once knew</td>
</tr>
<tr>
<td>She can’t understand how her mother changed in this way.</td>
<td>R: The changes were enormous uuu...the changes were enormous in her!</td>
<td>Questioning herself.</td>
</tr>
<tr>
<td>Her relative was never arrogant. Her mother used to correct Julia’s behaviour in how to respond to her brother’s</td>
<td>R: A lot, a lot, a lot. I’m telling you, whereas before she was a docile, sweet, full of humour and then all of a sudden, ‘Leave me alone, mind your own business, leave me you savage’ completely not being like my mother at all, do you understand? I can’t understand how my mother...from being such a gentle and docile person, not that she never got angry, however she wasn’t the type …</td>
<td>A shift in how her</td>
</tr>
<tr>
<td></td>
<td>I: I get you...I understand</td>
<td></td>
</tr>
<tr>
<td></td>
<td>R: to talk arrogantly or someone who</td>
<td></td>
</tr>
<tr>
<td>disability. However, with dementia she started to call her son ‘iblah.’</td>
<td>talked loudly. It was more likely the one to talk loudly I mean. Or my brother for example, when I was young I used to call him ‘stupid’, he has an intellectual disability, and she used to tell me ‘Of all the names you could call him, you call him stupid?’ and now she is the one to call him that!!! (emphasis). Heq... and she doesn’t do anything anymore, I mean, it’s a pity for example she used to go to church, and then I come home at around five to find her already asleep in bed because at first you start with a depression so your medications will be for a depresson until you start...because there is a hairline difference between depression and dementia.</td>
<td>mother was and is. Surprised and heartbroken</td>
</tr>
<tr>
<td>Julia felt surprised and heartbroken.</td>
<td></td>
<td>Encountering dementia problems.</td>
</tr>
<tr>
<td>Encountering dementia problems.</td>
<td>R: And in the beginning she was very (emphasis) uuuu ..I mean she used to fight with me… raising her hand..and I used to stop her, do you understand? So, I didn’t really know how to behave. Should I sort of be a little bit more fair and aggressive or should I be more gentle and kind? Nowadays I discovered that you have to be gentle and kind even though she is aggressive. But you’ll learn these things on your own, through experience.</td>
<td></td>
</tr>
<tr>
<td>Remembering how her mother was at first. She is very overwhelmed by her mother’s aggressive behaviour.</td>
<td></td>
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<tr>
<td>Nowadays (after a lot of years) she learnt to be patient and kind.</td>
<td></td>
<td>Learning as you go along.</td>
</tr>
</tbody>
</table>
Appendix F

Participants’ feedback

Dear Mr/Ms. [Surname],

Hope this letter finds you well.

Having your feedback is significant in this research. With your help I can further analyse and check the validity of my conclusions. As a researcher, I have held a detailed record of your interview, respecting anonymity, and summarized its findings, which you can find below.

Please, you are asked to confirm that the information provided is eligible to be used in my research and that it is an accurate representation of your beliefs. Also, ensure that the interpretations and data reductions made are fair and not distorted. Feel free to add any comments or suggestions.

If you have any queries do not hesitate to contact me on _________. Kindly send this letter by post in the self-addressed envelope enclosed.

I take the opportunity to thank you again for your time and effort.

Regards,

Deborah Spiteri
Main findings from your interview*:

______________________________________________________________________________

______________________________________________________________________________

I declare that the above data is:

a. Eligible to be used in the research and that it is an accurate representation of my beliefs.

   Yes  [ ]  No  [ ]

b. The interpretations and data reductions made are fair and not distorted.

   Yes  [ ]  No  [ ]

If ‘No’, specify why?

______________________________________________________________________________

______________________________________________________________________________

Comments/Suggestions:

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

*This information has been removed to protect the participants’ identity
Rispons minghand l-partecipant

[Address]

Ghażiż Sinjur/a [Kunjom],

Nispera li tinsab tajjeb/tajba.


Jekk ġhandek xi mistoqsija ħossok liberu/a li tikkuntattjani fuq __________. Jekk jogħġbok ibgħat din l-ittra fl-envelop li bghatt ma’ din l-ittra.

Nieħu l-opportunita’ biex nirringrazzjak tal-hin tieghek.

Dejjem tieghek,

Deborah Spiteri
Ir-riżultati misjuba mill-intervista tieghek*:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Jien/a niddikjara li dan ta’ hawn fuq huwa:

   a. Eliġibbli biex jintuża fir-ričerka u li huwa rappreżentazzjoni korretta tat-twemmin tiegħi.

   Iva  [ ]     Le  [ ]

   b. L-interpretazzjonijiet u tqassir ta’ l-informazzjoni huma konsistenti u bl-ebda mod m’huma miftehma hażin.

   Iva  [ ]     Le  [ ]

Jekk ‘Le’, għaliex?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Kummenti/Suġġerimenti:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

*Din l-informazzjoni mneħħija biex tipproteġi l-identita’ tal-partecipant