Dissertations   Social Sciences

2014

An Exploration of the Experiences of Individuals Caring for a Family Member and the Impact this Caregiving Role has on their Lives.

Tara Duigenan
Technological University Dublin

Footer logo

Dissertations

Social Sciences

2014

An Exploration of the Experiences of Individuals Caring for a Family Member and the Impact this Caregiving Role has on their Lives.

Tara Duigenan
Technological University Dublin

Follow this and additional works at: https://arrow.tudublin.ie/aaschssldis

 Part of the Social and Behavioral Sciences Commons

Recommended Citation

An exploration of the experiences of individuals caring for a family member
and the impact this caregiving role has on their lives.

Tara Duigenan

Submitted to the Department of Social Sciences, Dublin Institute of
Technology in partial fulfilment of the requirement leading to the award of the
Masters of Arts in Child, Family and Community Studies.

Supervisor: Dr. Ann Marie Halpenny

MA in Child, Family and Community Studies   2014

Declaration

I hereby certify that this material, which I now submit for assignment on the programme of study leading to the award of Master of Arts in Child, Family and Community Studies, is entirely my own work and has not been submitted for any academic purpose, other that the partial fulfilment of that stated above.

Signed _____

Date _____

Word Count: 14,994

Abstract

Ireland, in keeping with most western societies has witnessed a steady increase in the distribution of old and very old individuals in the population. This, combined with escalations in degenerative and chronic diseases, and together with the development of new sophisticated and portable medical technologies that assist people with highly complicated health conditions to be cared for at home, places further demands on individuals to care for a family member. Furthermore, a fundamental objective of Irish Government policy for older people, children and adults with a condition or a disability is to enable these individuals to live in dignity and independence, in their own homes and communities for as long as they can. Carers are central to the success of this endeavour. As such, it is vital that the experiences of carers and impact of caring are considered.

This study set out to explore, through qualitative, semi-structured interviews, the experiences of individuals who care for a family member and the impact that this has on their lives. Seven participants in this study were full-time family carers, while two further participants worked as family carer support workers and had an abundance of knowledge in this area. The findings relating to the experience of family carers arose under four broad headings:

1. Motivations to care
2. Impact on life
3. Formal support
4. Positive aspects of providing care

From the nine interviews common themes were identified, conclusions were drawn, and recommendations for future research, policy and practice were made.

Acknowledgements

Table of Contents

Chapter Five: Discussion of findings

Chapter Six: Conclusion

List of Appendices

CHAPTER ONE: INTRODUCTION

1.1   Introduction

This study explores the experiences and views of family carers. The main areas considered in this study are guided by the experiences of the participants, highlighting its exploratory nature. This study adopted a qualitative approach, using semi-structured interviews, with seven individuals who had experience in providing care to a family member, and two care support workers, who had a wealth of experience in the area of family carers. All participants in this study either worked with, or were members of a caring organisation.

Though the sample is small, the interviews highlight areas of particular importance in providing care for a family member. Due to the sample size however, findings from this study cannot be considered representative of the general family carer's experience. This chapter will commence by listing the aims and objectives of this study, the rationale for the study will then be described, followed by an outline of the study.

1.2   Aims and objectives of the study

The main research question of this study is to explore the experiences of individuals caring for a family member and the impact this caregiving role has on their lives.

Key research objectives include:
- To explore the motives behind providing care to a family member.
- To gain a greater understanding of the impact caring has on carers.
- To identify and understand key challenges of providing care to a family member.
- To explore perceived positive aspects of caring for a family member.
- To understand what factors contribute to positive and negative caring experiences.

1.3   The idea of care

For the purposes of this research the Central Statistic Office's (CSO) definition of a carer is used. The CSO (2010, p. 2) states that a carer is a person who

> '*Provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems which are due to old age). Personal help includes help with basic tasks such as feeding and dressing.*'

Informal carers are individuals who provide care, on an unpaid basis, to others who require help or support. Generally, informal care is delivered by family members of the person in receipt of care. Informal care or family care is differentiated from formal care services, as the care is usually delivered free of charge and is not regulated by the state. Although family care is delivered at no cost, as the Care Alliance (2013) discusses, it is not free of charge in an economic purpose, as time devoted to caring is time that cannot be focussed on other endeavours such as paid work, education, volunteering or leisure.

1.4   Rationale for this study

Many authors have commented on the growing prevalence of family carers. The findings of CSO indicate that there was a 13.7 percent increase in the number of unpaid carers between the 5 year period of 2002 and 2006 (Care Alliance, 2013).

According to the European Commission (EC) (2008) it is predicted that the number of individuals aged 65 and over will have increased by 77 percent by 2050. As discussed by Glendinning, Tjadens, Arksey, Morée, Moran & Nies (2009), an ageing population denotes a growing distribution of old and very old individuals in the population, with escalations in degenerative and chronic diseases leading to new patterns of morbidity. Granted, increased age and chronic disease do not consequentially result in a need for care,

demographic ageing still functions as a useful gauge of demand for long-term care (EC, 2008). The development of new sophisticated and portable medical technologies that assist people with highly complicated health conditions to be cared for at home, place further demands on individuals to care for a family member.

Although trepidation has been voiced about the effect of population ageing and developments in medicine and technology on family carers, recent analysis of family trends in Ireland signifies that there is a renewed capability among families to deliver care for relatives (Lafferty, Fealy, Downes & Drennan, 2014). This is as a result of the change in the family formation of older people in recent years. Previously, a large percentage of older people were single, with no children, whereas in recent years, a large proportion are married and have adult children (ibid). However, this example of care, fortified by family networks of support may weaken and become untenable due to changing family structures and sizes in Ireland, and trends in women's participation in the labour market (Care Alliance, 2013). Additionally, the readiness and resilience of family members to be responsible for care is indefinite, and may be challenged by the increasing number of older people with high dependency needs (Fahey & Fields, 2008). Therefore it is important to explore the experiences of individuals caring for a family member and the impact this role has on their lives.

1.5   Conclusion

Despite the prevalence of carers, the increasing older population and developments in medicine and technology, there is a lot that is unknown about the experience of carers. It is imperative that a well-rounded study of family carers is borne, taking into account all aspects of the caring experience. Thus, the present study sought to address this. The specific focus of this study was the family carer and his or her interpretation of their caring experience. While

the sample was small, it was foreseen that the study may contribute to a greater understanding of the caring experience of individuals caring for a family member and the impact this role has on their lives.

1.6   Outline of this study

Chapter Two: Literature review of family carer research.

This chapter considers Irish social policy in relation to carers and introduces the theoretical model of caregiver stress, put forward by Pearlin, Mullan, Semple & Skaff (1990). This chapter then proceeds to examine the motivations behind providing care, the impact care has on different aspects of life, such as employment, health and social participation. Finally, this chapter considers the positive aspects of providing care for a family member.

Chapter Three: Methodology

This chapter describes the methodology of the current study. The selection of the research design is rationalised with regard to the research question and objectives and the interpretive phenomenological approach is discussed. This chapter then proceeds to outline the research sample and selection, the research instrument, ethical issues, data collection procedures and data analysis.

Chapter Four: Findings

This chapter presents the findings of the semi-structured interviews with the various participants. These findings are organised by themes, which are additionally divided into sub-themes to categorise key topics which transpired.

Chapter Five: Discussion

This chapter discusses the findings of the interviews. These findings are evaluated in terms of relevant family carer literature.

Chapter Six: Conclusion

This chapter depicts a conclusion to this research study. Included in this chapter are recommendations for future research, policy and practice.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter presents a literature review on the topic of family carers. It begins by considering Irish social policy and supports relating to family carers. This is followed by an outline of Pearlin *et al.*'s (1990) theoretical model of caregiver stress, 'The *Stress Process*'. Finally this chapter examines the key issues which emerged from a comprehensive review of family carer literature.

2.2 Irish Social Policy

A fundamental objective of Irish Government policy for older people, children and adults with a condition or a disability is to enable these individuals to live in dignity and independence, in their own homes and communities for as long as they can. Carers are central to the success of this endeavour and are regarded as the mainstay of care provision in Ireland (Department of Health, 2012). According to the Irish Longitudinal Study on Ageing (TILDA), internationally families remain to be the most important supplier of care for dependent older people (Barrett, Savva, Timonen & Kenny, 2011). The *National Action Plan for Social Inclusion 2007-2016* acknowledged the part that family carers play in aiding Government policy of caring in the home and community, and it advocated that carers need a variety of supports including financial supports, education and training (Government of Ireland, 2007).

According to the Care Alliance (2013) the *National Carers' Strategy* has been considered a crucial landmark in support for, and in acknowledgement of family carers in Ireland. Central to this strategy, are the objectives of:

- Acknowledging the value of carers and contribution they make.
- Endorsing the inclusion of carers in decisions involving the individual they care for.
- Assisting carers to sustain their own health and wellbeing.
- Assisting carers to have confidence in their caring through the delivery of information, training and support.

- Empowering carers to contribute as wholly as they can in economic and social life.

However, the Care Alliance (2013) describe this strategy as inadequate in some areas, as it poses no assurance to fully protect current income supports.

2.2.1 Income support

Carers can apply for income support from the governmental Department of Social Protection. The Carer's Allowance is a means-tested form of income support which is available to carers who care for people in need of full-time care and attention (Department of Social Protection, 2014). Individuals in receipt of a social welfare payment may be entitled to a half rate Carer's Allowance. The Carer's Benefit is a payment for people who have paid social insurance contributions and who leave employment for up to two years to care for an individual who requires full-time care (*Ibid*). Despite this, just 13 percent of carers receive a Carer's Allowance or a Carer's Benefit (Kamiya, Murphy, Savva & Timonen, 2012).

2.2.2 Formal Services

The Health Service Executive (HSE) offer home care packages, involving community services, such as community-centred nursing, therapies, home help services, day care and respite care, which are customised to meet each dependent older person's requirements and situation (HSE, 2013). Respite services are regarded as vital as they provide family carers with an opportunity to spend some time away from the responsibility of caregiving (Lafferty *et al.,* 2014).

2.3 Theoretical framework

Though caregiving can have positive and negative effects, the negative effects are by far the best documented. Models purporting to explain both the positive

and negative outcomes of caregiving experiences are primarily based in literature on stress and coping. Prevalent among conceptual models of caregiving is the notion that the commencement of chronic illness, frailty and functional decline grows stressful for the carer and the care recipient over duration of time (Schulz & Martire, 2004). The most renowned model used to understand the stress experienced by caregivers is the *Stress Process Model*, developed by Pearlin *et al.* (1990) (Quinn, Clare & Woods, 2010; Lafferty *et al.,* 2014).

2.3.1   The *Stress Process Model*

The *Stress Process Model* aims to identify the conditions related to stress, and how these relate to each other; consequently psychological distress is regarded as the outcome of the stress process. This model studies the interrelationship of the carer's socioeconomic background, both primary and secondary stressors, and the effect of these on the carer (Pearlin *et al.,* 1990). The objective primary stressors relate to markers, which signify the difficulties of the caring role and are attached to the needs and demands of the care recipient, for instance, cognitive status, difficult behaviour and dependency. The subjective primary stressors relate to difficulties personally experienced by caregivers, such as overload or burnout and relational deprivation where the caregiver feels detached from different parts of their life. The secondary stressors concern role strain, regarding roles and activities external to providing care, such as family conflict, employment conflict, economic difficulties, and restriction of social life. Secondary subjective stressors are associated with self-esteem, mastery, loss of self, role captivity, competence and gain. The outcomes for carers in this process may include depression, anxiety, irritability, cognitive disturbance, negative impact on physical health and surrendering of their role as caregiver (Lafferty *et al*., 2014). This model has been criticised however, for its emphasis on the negative outcomes of

caregiving, more recent research has started to examine some of the positive aspects of caregiving, such as gratification (Kramer, 1997).

2.4 Positive aspects of providing care

Research on caregiving has excessively concentrated on negative elements; a more thorough approach is required, if caregiver experience is to be entirely appreciated (Kramer, 1997; Green, 2007). Research has found that although carers have reported feeling both stress and joy as a result of providing care, they express rather more joy than stress (Kolmer, Tellings, Gelissen, Garretsen & Bongers, 2008). Cohen, Colantonio & Vernich (2002) established that over 70 percent of carers in their study were positive about their caring role, citing positive traits such as companionship, fulfilment, reward, enjoyment, and the satisfaction of meeting an obligation and providing quality of life to a loved one. Similarly, parents of children with an intellectual disability focused on the positive aspects of their lifelong caregiving role, and the positive effect it had on the quality of their family life (Jokinen & Brown, 2005). Correspondingly, Lopez, Lopez-Arrieta & Crespo (2005) observed that regardless of challenges, carers largely conveyed great satisfaction in delivering this support, stating it had brought them closer to their loved ones and had given meaning to their existence. Wolff, Dy, Frick & Kasper (2007) indicated that a greater number of end-of-life primary carers recognised personal rewards associated with their role, over emotional, physical and financial stresses, with 70 percent affirming that caring empowered them to appreciate life more. O'Reilly, Connolly, Rosato & Patterson (2008) found that carers were less likely than non-carers to report the presence of a limiting long term illness.

Many authors recognise the positive impact the caring role has a on the life of the carer and their relationships with the care recipient (Hales, 2007; Hughes, 2007; Donelan, Hill, Hoffman, Scoles, Hollander Feldman, Levine *et al.,* 2002). Smebye & Kirkevold (2013) found in many caring situations

interdependence supported family unity. Similarly, Packenham (2005) established that as a result of caregiving, there was a growth in family relations between the family and the care recipient. Kiely (1999) also believes that the growth in the frequency of caring and multi-generation family units determines that there is relatively low conflict of interest among the various generations, suggesting that intergenerational solidarity within families remains strong.

2.5   Difficulties associated with caregiving

It is important to recognise that caregiving can be an enriching and rewarding experience. However, caregiving can also be difficult on the carer and on many aspects of their lives, such as employment, physical health, mental health and participation in social life (Pinquart & Sorensen, 2007; O'Sullivan, 2008; O'Brien, 2009; Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Care Alliance, 2013).

2.5.1   Employment difficulties

Research has found that family carers are less likely to be employed and are more likely to work solely within the household, as a home-maker, than non-carers (Colombo *et al.,* 2011). Similarly, almost half of Australian female carers who are unemployed were in employment before they began caring (Edwards, Higgins, Gray, Zwijewski & Kingston, 2008). Stiell, Shipton & Yeandle (2006) found that most parents, who care for a child, indicated that caregiving had a negative effect on their own employment. They believed that caring had an adverse impact on relationships with colleagues, and believed that opportunities of advancement were refused to employees with caring responsibilities.

Restricted labour force involvement does not only indicate lower employment rates but also suggests a lower frequency of full-time

employment. Colombo *et al.* (2011) found that even when employed, carers work approximately two hours less per week than other adults, while they are also more likely to be over-represented in part-time employment. Caring responsibilities can influence career stability and job choices, possibly explaining the high rates of carers who are employed in part-time, temporary employment. Similarly Stiell, *et al.* (2006) ascertained that while some carers had changed their working arrangements or reduced their hours of work to assist with their care-giving responsibilities, many felt obligated to change their job.

According to the Colombo *et al.* (2011) working-age carers are at a high risk of poverty. Carers UK (2007) accounted that carers lost an average of approximately €12,300 in earnings in the year prior to their study. This was due to leaving employment, reducing employment hours or adopting a more low-ranking position. The longer the quantity of time spent caring each week, the more money was lost. Carers in their late fifties and early sixties, and those caring for a parent or partner encountered the greatest loss in income. Carers also recounted struggling to pay for important services such as gas, electricity or the telephone, being unable to afford essential household repairs and using their own income or savings to pay for services for the person they were caring for (Carers UK, 2007; Tjadens, Vissser & Sangers, 2008).

2.5.2 Physical health difficulties

It has widely been established that family carers are more than twice as likely to report poor or very poor quality of life, and they are more liable to report poor health than other adults (Singleton, Aye-Maung, Cowie, Sparks, Bumpstead & Meltze, 2002; Pinquart & Sorensen, 2003; Vitaliano, Zhang, & Scanlan, 2003). O'Sullivan (2008) found that just over one third of carers described their health as excellent or very good, in comparison to almost half of the adult population as a whole. In contrast O'Brien (2009), in his study on

the health of Irish family carers found that the majority recounted their health as '*quite good*' or '*very good*', however, more than half of his sample described feeling mentally and physically '*drained*' as a result of their caring responsibilities. O'Brien (2009) found that aspects of caring, such as coping with verbal and emotional abuse; handling unusual and unpredictable behaviour; and getting up throughout the night were the kinds of caring tasks most related to causing bad health. More than half of the participants involved in this study described having a medical problem such as back injuries or mental health problems such as anxiety disorders.

Edwards *et al.* (2008) found that while in the general population, the percentage of people reporting poor physical health increases with age, the proportion of carers experiencing poor physical health is comparable for all carers aged 35 years or over. This signifies that the frequency of poor physical health among carers may not relate directly to ageing process, but instead to physical and other injuries caused by caring. Similarly, Stokes (2010) and Burton, Zdaniuk, Schulz, Jackson & Hirsch (2003) found that caregivers reported negative health effects, especially when providing on-going care or when transitioning to extremely demanding physical and emotional care-giving, for instance in the situation of caring for people with Dementia.

Carers Scotland (2011) found that family carers had twice the prevalence of long-term illness and disability as the rest of the population; over half of participants indicated evidence of long-term illness or disability, including those who regarded their health as average or good. Many participants had more than one long-term condition, while more than two thirds of participants suffered problems such as joint, hip, back or neck pain, with more than a third suffering from varying forms of arthritis. Approximately half of these carers described their conditions as starting after they commenced caring, of those whose condition pre-existed, a quarter stated

it had worsened since they started providing care. Similarly, Stokes (2010) found that conditions such as high blood pressure, tiredness, lack of energy, back problems and arthritis were all regarded as adverse effects of caring.

2.5.3 Mental health difficulties

It has been established that carers present higher rates of mental health problems across Organisation for Economic Co-operation and Development (OECD) countries (Colombo *et al.,* 2011). It was found that carers have considerably higher levels of depression and stress, and poorer measures of subjective wellbeing than that of non-carers (Adams, 2007; Spector & Tampi, 2005; Pinquart & Sorensen, 2004). Family carers have the lowest levels of personal wellbeing or life satisfaction of any of the demographic groups; including individuals living alone and unemployed individuals, with most carers experiencing depression at acute, severe or moderate levels (Cummins, Hughes, Tomyn, Gibson, Woerner & Lai, 2007). Among the caring-population the incidence of mental health problems is 20 percent higher than that of non-carers. However, when considering high intensive caring, this level rose to 70 percent and even 80 percent. Low intensity caring conversely, does not always equate to a higher occurrence of mental health problems in carers than among non-carers (Colombo *et al.,* 2011).

Stressors associated with carers' depression included the behavioural problems of the person with a condition or disability; high hours of caring per week; time pressures; whether the cared-for had cognitive or physical impairments; and the number of caregiving responsibilities (Pinquart & Sorensen, 2004; McGarrigle & Kenny, 2013).

Providing care to a spouse and providing care to individuals with Dementia have been found to be acutely stressful; noticeable differences have been observed in the depression and stress levels of carers who cared for

spouses when assessed with that of non-carers (Pinquart & Sorensen, 2004; Schulz & Martire, 2004; Bertand, Fredman & Saczynski, 2006). Cooper Selwood, Blanchard, Walker, Blizard & Livingston (2010) investigated abusive behaviours experienced by carers of people with Dementia, and found that almost half of carers recounted that the care recipient was abusive in the previous months and more than one third of the sample reported the care recipient was abusive, '*at least sometimes*'. Carers who provided care to people with Dementia have described the highest levels of stress and greatest loss in psychological wellbeing (Pinquart & Sorensen, 2004).

2.5.3.1   *Carer Stress*

It has been recognised that the greater the intensity in the nature or extent of care provided, the greater the scale of health effects on the carer, predominantly as a result of chronic stress (Schulz & Sherwood, 2008; Burton *et al.,* 2003; de Boer, Brose van Groenou & Timmermans, 2009; Yeh & Bull, 2012). Feelings of loneliness, anxiety and depression were directly associated with the demands of caring (Stokes, 2010). As an individual's health deteriorates the demands placed on the carer escalate and may reach a perilous level, with the carer experiencing stress or burden (Nerenberg, 2008; Dale, Sævareid, Kirkevold & Söderhamn, 2008; Lee & Kolomer, 2012). However, as Stirling, Andrews, Croft, Vickers, Turner & Robinson (2010) argue, due to the particularly challenging circumstances carers find themselves in, even minor care recipient demands may cause tremendous stress to the carer.

Care-givers who suffer elevated intensities of stress may be obstructed in their capability to perform well in their position as an enduring support network for the care recipient. It is crucial to note that as a carer is an indispensable component of home care, if the burden on a caregiver becomes too pronounced, the support may be completely threatened (Donnelly, 2013). Nerenberg (2008) hypothesizes that if caregiving reaches a level whereby a

perilous amount of stress is experienced, carers may then resort to abuse or neglect. This abuse is related to carer stress or to the responsibility of the caregiving itself, rather than to cruel intent on the part of the caregiver to harm the care recipient (Marshall, Benton & Brazier, 2000). Therefore, ensuring the wellbeing of family carers, especially in relation to mental health is essential, both for the carer and care recipient (Lafferty *et al.,* 2014).

2.5.4 Social Participation

Responsibilities associated with caring often reduce the time available for family carers to have a life of their own. Many do not have access to supports to allow them significant time off from their caring duties to have a social life or to more generally participate in the community and wider society (The Carers Association, 2008). Family Carers have reported major restrictions on their social or leisure activities, personal interests and hobbies; with isolation being a problem for many (Hynes, Stokes & McCarron, 2012). Research has indicated that more than half of carers of older people across Europe reported problems keeping in contact with friends, feeling '*trapped*' by their caring responsibilities, poor emotional wellbeing or feelings that caregiving was too challenging (Glendinning *et al*., 2009). Conflicts with spouses or children due to a lack of time for them, social isolation and feelings of loneliness, were also commonly reported. Similarly, Saunders (2011) found that 41 percent of family carers stated that they encounter loneliness frequently or almost always.

In contrast, Australian research has established that over half of carers believed their circle of friends was unaffected by caregiving; a small minority of participants indicated that their circle of friends had grown as a result of their caring role (Australian Bureau of Statistics, 2004). Nevertheless, almost a quarter of carers described how they had lost or were losing contact with existing friends since they had started caring. Correspondingly, Saunders (2011) outlines the demanding nature of the caring role and the way in which

it disconnects family carers from previous social networks; over half of participants ranked their social life as non-existent, very little or limited to the monthly carer support group meetings. As the duration of caring increases and levels of care intensify, this can result in negative feelings of frustration and sacrifice of self among family carers (Stoltz, Uden & Willman, 2003). Due to the demands of caregiving, carers often place their own needs on hold for the future, and as a result they can experience a lack of freedom and feelings that they do not have a life of their own (Stoltz *et al.,* 2003; Orpin, Stirling, Hetherington & Robinson, 2014).

Research has also indicated that although carers in rural areas have the same needs as carers living in other areas, social problems can be exceptionally severe for rural carers, as a result of a lack of specialist services and respite, difficulty in accessing medical support, isolation, information gaps, lack of other options to family care and poverty (Orpin *et al.,* 2014).

2.6   Informal supports for carers

Research has found that informal support delivered by friends or relatives had the strongest association with carers' wellbeing (Pinquart & Sorensen, 2007). Japanese research indicates that carers of older people who received temporary respite from their caring responsibilities report lower levels of stress (Arai, Kumamoto, Washio, Uda, Miura & Kudo, 2004). Correspondingly, Yeh & Bull (2012) and Cecil, Thompson, Parahoo & McCaughan (2012) reported substantial positive links between lack of family support and family caregiver stress (Yeh & Bull, 2012).

2.7   Motivation behind providing care

The literature on the general motivation to provide care to a family member, typically defines motivation as either intrinsic or extrinsic (Ryan & Deci, 2000). Intrinsic motives include love, altruism, close kin relationships and

reciprocity, while extrinsic motivations include caring due to societal expectations and cultural values, and providing care as a result of guilt, duty, responsibility and lack of choice (Smebye & Kirkevold, 2003; Camden, Livingston & Cooper, 2011; Quinn *et al.,* 2010; Wallhagen & Yamamoto-Mitani, 2006; Lyonette & Yardley, 2003). Caring as a result of intrinsic motives, are largely considered to have more positive effects on the caregiver than extrinsic motives (Smebye & Kirkevold, 2003; Camden *et al.,* 2011; Lyonette & Yardley, 2003).

The construction of choice in caregiving may well be restricted by linguistic and/or cultural variation. It is possible that as a result of culture and the associated social norms and expectations, some caregivers may find it difficult or impossible to refuse to provide care (Wallhagen & Yamamoto-Mitani, 2006; Ho, Friedman, Rappolt & Noh, 2003). For some individuals, cultural values and identities may prevent recognition that choice even exists. Consequently, those who recognise caregiving as a '*given*' can experience caring differently to those who have a choice in the matter (Kietzman, Benjamin & Matthias, 2013). Authors have found that where caring is predominantly prompted by a sense of duty and obligation rather than love and affection, these situations are characterised by long term caring relationships, which leave family carers weary and exhausted. The carers' own needs were abandoned and future plans obstructed, leading to upset and frustration (Smebye & Kirkevold, 2003; Lafferty *et al.,* 2014). Similarly, individuals who supplied care as a result of the absence of other options, or because they wanted to avoid the admittance of an elderly relative to a care home, were liable to find caring a burden; carers described feeling '*strangled*' by their own sense of obligation and duty (de Boer *et al.,* 2009; Ho *et al.,* 2003).

2.8   Conclusion

This chapter presented the key constructs which emerged from a review of family carer literature. It firstly examined Irish social policy and supports in relation to family carers, this was followed by a brief outline of Pearlin *et al.*'s (1990) theoretical model of caregiver stress, '*The Stress Process'*. Lastly, this chapter examined the key issues such as the positive aspects of providing care to a family member, difficulties associated with providing care and motivations behind caregiving. The following chapter will outline the research design for the present study.

CHAPTER THREE: METHODOLOGY

3.1   Introduction

This chapter provides an overview of the chosen research methodology with regard to the core objectives of the present study. The purpose of this research was to explore the experiences of individuals caring for a family member and the impact this caregiving role has on their lives. This study implemented a qualitative approach to exploring the topic of caring, using semi-structured interviews with nine participants. Seven of the informants were members of a Caring Organisation and provided full-time care to a family member, while two participants worked for a Carer Organisation, and had a wealth of knowledge in this field. This chapter will consider the rationale for the research design, followed by an outline of the sample selection, research instrument, research procedure, ethical issues and data analysis method.

3.2   Research Design

Denscombe (2010), Silverman (2006) and Creswell (2009) emphasise the importance of employing a research design that is appropriate to the purpose of the research. Qualitative research seeks to understand, rather than to measure, lending itself to an exploratory insight into the experiences, understandings, behaviours, attitudes and values from the perspective of the research participants (Denscombe, 2010; Creswell, 2009; Sarantakos, 2005). Consideration was given to quantitative survey research; however a method such as this would only lead to statistical results, which would not be as beneficial as data obtained through qualitative methods. Although statistical findings can be extremely advantageous it is apparent that this method would not contribute greatly to achieving informal carers views and experiences of care and its impact on their lives. As the main aim of the present study was to explore the subjective experiences of family carers, a qualitative approach was considered to be most suitable.

Qualitative techniques have numerous strengths; they expose the various circumstances that individuals find themselves in and offer superior flexibility, allowing the researcher to attain a more meaningful conceptualisation of informants' particular experiences (Sarantakos, 2005). The qualitative approach delivers a wealth of detail, gained from the informant's subjective musings on their caring role. In depending on the participant's individual insight the researcher can obtain a contextual understanding and a depth to the study (Guthrie, 2010). It is however, imperative to observe that under the qualitative approach the ideas, values, beliefs and understandings of the researcher may perhaps influence the study.

3.3   Interpretive Phenomenological Approach

The values of an Interpretive Phenomenological Approach (IPA) underpinned this research strategy. Bryman (2012) defines interpretivism as a body of knowledge that obtains subjective understandings from social actions and interactions of individuals within the social world, where individual experiences are considered to be fundamental to how the research is examined. This method is idiographic; it is predominantly preoccupied with how people make sense of their life experiences (Denscombe, 2010). The IPA places importance on what ensues when the daily sequence of lived experiences assumes particular significance for the individual, for instance major life transition. Consequently, the emphasis is on what this occurrence is like for the individual and interpretivism strives to deliver an accurate interpretation of the individuals account, in a manner that is true to the original (Denscombe, 2010; Schutt, 2003).

Interpretivism is underpinned by hermeneutics; the philosophy of interpretation. The IPA researcher is immersed in a double hermeneutic, as they strive to make sense of the informants effort to make sense of their experience. The only access to this understanding is through the informants'

description of it (Schutt, 2003). The interpretive element of the IPA acknowledges that our life experiences unavoidably influence our understanding of events, and that the researcher will generate some subjectivity and bias in the investigation. As a result, the researcher occupies an important position in the explanation and analysis of data (Denscombe, 2010).

3.4   Research Sample and Selection

Guthrie (2010) notes that in order to produce valid and trustworthy research, the researcher must endeavour to generate an accurate sub-group of the research population. Thus, in choosing a sample it is vital that while it may not be wholly representative, it must as a minimum, have the specific characteristics which are important in the investigation of the broader issue (Denscombe, 2010). The criteria involved in the selection of the research sample are fundamental to the reliability of any investigation (IBID).

In selecting participants for this research snowball sampling was employed. Under this sampling technique several Carer Organisations were identified and contacted by email (see Appendix E) detailing the research that was being undertaken and requesting permission to interview members of the organisations on their experiences of caring and its impact on their lives. Two separate organisations were eager to help, and gatekeepers organised members to participate. The gatekeepers organised nine interviewees, seven of these participants were full-time carers, between the ages of 45 to 63. The types of care which participants provided varied; some carers provided care to disabled children or adults, while others provided care to elderly parents with varying conditions such as Dementia, Chronic Obstructive Pulmonary Disease (COPD), Diabetes, Stroke and limited mobility. Two further participants were employees of these carer organisations, these participants worked alongside family carers, as carer support workers within these organisations. The sample

comprised of eight females and one male (see Appendix A for table of participants).

3.5   Research Instrument

A range of qualitative research instruments were considered, such as interviews; structured and semi-structured; participant observation and focus groups. In-depth, semi-structured interviews were deemed to be best suited to this study, as will be presented below.

Denscombe (2010) advocates that in the examination of a complex issue, interviews are best utilised as a mode of data collection. Additionally, Denscombe (2010) proposes that in-depth interviews are above all, suitable for the compilation of sensitive and confidential information, which necessitates awareness into individuals' opinions, emotions and experiences. Structured interviews, because they are more prescribed, may limit the development of significant data, essential to the research question and the idea that each person's experience is unique.

Semi-structured interviews involve devising a set of questions to be put to participants, providing structure to the interview. Semi-structured interviews present clear topics to be explored but also have flexibility to permit individuals to develop on themes of interest, which reveals the wealth and complexity of experiences.

In-depth, semi-structured interviews are one-to-one; therefore they allow participants to express their own opinions without feeling the need to conform to the ideals of a group (Schutt, 2003). This method allows the participant to answer on their own terms and to demonstrate their own views and experiences. As highlighted by Silverman (2010), semi-structured interviews are conversational; they allow the interviewer to delve beyond the

answers given by the participant in order to achieve elaboration and clarification about the answers given. This method of data collection is greatly advantageous to this research as it is humanistic, providing the researcher with subjective experiences. Often, the experiences of individuals may highlight previously overlooked aspects of policy, or they may in fact raise new issues. This type of data collection allows the researcher to gain an understanding of the informant's viewpoint which will be vital in exploring the experiences of carers and the impact of the caring role on the carer (see Appendices B and C for the list of interview questions).

3.6 Ethical Issues

Ethics were of fundamental importance throughout this research. As in all research undertakings, there is an onus on the researcher to protect their research participants (Denscombe, 2010). Bryman (2012) proposes that ethical considerations must not be overlooked as they directly relate to the integrity of a piece of research and to the disciplines that are involved. Informed consent is imperative; as discussed by Schutt (2003) this means that participants must know that they are being researched and they have a right to be informed about the nature of the research and to withdraw at any time. With regard to the present study the researcher was completely overt with the participants as to the nature and purpose of the research. A letter to participants was compiled (see Appendix F), which describes the purpose of the research and informed the participant that they had the right to withdraw from the research at any time until the research was completed. Each informant read the participant information letter and signed a consent form (see Appendix G) before the interview commenced.

In order to protect the privacy of the informants, each informant was provided with pseudonyms and all names of people and places discussed in the interviews were changed in the transcription process. Participants were

informed that interviews would be recorded and disposed of immediately after transcription. This guarantees confidentiality and safeguards each participant's privacy and freedom to partake. In signing this form, it is confirmed that the researcher receives voluntary, informed consent. The recordings and transcripts were handled and stored with the highest level of discretion and this information will be used exclusively for the purpose of this research.

As the topic of caring constitutes a sensitive subject, it had the potential to cause some distress to participants. It is important to note that the researcher was sensitive throughout the interviews with regard to the subject matter discussed. After each interview the researcher confirmed that the participant was not in any way impacted negatively by the interview. The fact that these participants were members of Carers Organisations provided a further support, should they have needed it.

3.7   Data Collection Procedures

Firstly, Carer Organisations were identified as having potential participants. Emails were compiled, detailing the nature of the study, its aims and objectives and requesting if members of the organisations would be interested in participating in the study. These emails were then distributed to the relevant Carer Organisations. On receiving correspondence from these organisations, denoting interest in participating in the research, letters to potential participants were compiled to ensure that participants were informed about the nature of the research. Consent forms were then compiled, which were signed by participants prior to the interview. These steps ensured the researcher received voluntary, informed consent, as previously discussed.

Interviews were organised to take place within an empty office, in each organisation's branch. The setting of the interview and the environment in which it takes place are matters which can affect the depth of the data gathered

(Denscombe, 2010; Creswell, 2009). Supplying a relaxed, non-threatening, stress free atmosphere for the informant delivers an environment that will generate more descriptive and authentic responses. Denscombe (2010) highlights that characteristics such as sensitivity and attentiveness, and a comprehension of when it is suitable to prompt or probe, promote a richer, more thorough interview.

On average each interview lasted approximately 40 minutes. All interviews were digitally recorded and all participants were alerted to this prior to agreeing to participate in the research. The interviews were fully transcribed, verbatim with annotations included such as non-verbal communications, pauses and other important observations.

3.8   Data Analysis

By listening and re-listening to the recorded interviews, reading and re-reading the transcriptions of the interviews, an analysis of the subject matter of the interviews can take place. Thematic analysis encompasses recognising themes or categories that concern the study (Bryman, 2012). As noted by Marshall & Rossman (2006) this permits the researcher to identify material from the crude data and establish links between the research question and the findings. The data were assessed to detect comparable themes discussed by interviewees. These data were then categorised into similar topics. As discussed by Denscombe (2010), the commonalities in the sample and preceding knowledge examined in the literature review will inform the findings of the research.

Bryman (2012) explains how a framework of themes and sub themes can arise through repetitive themes within the transcripts. However, Bryman (2012) highlights that the recurrence of a subject alone does not merit it being regarded a theme. Rather, it is imperative that the researcher considers the connections between themes, the tone of the conversation and frequently by

contemplating what was not said (Bryman, 2012). Bearing these principles in mind, the first stage of coding concerned a broad identification of the significant themes occurring by employing a colour coding strategy. As themes occurred, appropriate segments of the data were colour coded and assembled to elaborate on and bolster the appropriate themes. A second stage of coding then acknowledged sub themes which were highlighted and assembled with the appropriate data to clarify and support these themes. A final stage of coding permitted the researcher to tie together fundamental themes and sub-themes comprehensibly and to additionally elaborate on the connections and meanings evolving from the data.

3.9 Conclusion

This chapter has described in detail the methodology of this research study. The interpretivist approach has been portrayed as a central part of the research strategy, though this approach may have limitations, the strengths of this approach validated its selection as the basis of the research strategy. This chapter then went on to examine the research sample, the research instrument, ethical issues, data collection procedures and finally, data analysis. The following chapter will present an account of the research findings.

CHAPTER FOUR: FINDINGS

4.1   Introduction

This study explored the experience of individuals caring for a family member and the impact this caregiving role has on their lives. The analysis of empirical data established central aspects of the experience of carers, which held great significance for the participants. This chapter will outline and present the main themes that arose from the qualitative interviews with family carers and carer support workers. The participants' views will be presented under the broad headings of motivation to care, the impact of care on the family carer, supports and the positive aspects of care. Furthermore, these themes will be divided into sub-themes, to outline certain aspects of the themes which developed from the narratives.

4.2   Motivation to care

The motivation to care emerged as a key finding of this study. Participants described how their motivation to care for a family member significantly impacted upon their experiences of caring. The subsequent section will describe the findings of the motivation to care in greater detail.

4.2.1   Love and duty to a family member

The relationship between the parent and child, and also husband and wife emerged as a strong determinant of the experience of carers. These relationships appeared to be the main motivator for care. Individuals discussed how it was their duty to care for the particular family member.

4.2.1.1 Relationship between parent and child

When asked to describe their motivation for caring, individuals who cared for a child described how it was not a choice, there was no question as to whether they would not do it, it was a significant part of their role as a parent, and thus providing care was inevitable.

"I brought him into the world, he's my child. There was never any question as to whether or not I would look after him. The fact that he needs more care than other children doesn't come into it. He's my child; I'll care for him for however long he needs it." (Anna)

Parents also believed that in caring for their child they were enabling them to live the best life possible. In these cases parents believed that caring for a child, rather than admitting them into a residential care home allowed the child to develop to the best of their ability, not only physically but personally, through the establishment of close relationships with other family members and family friends.

"When he was small there was talk of a residential care home, but as far as I was concerned it was out of the question. By looking after him, at home, at least I knew that I would give him every opportunity I possibly could. I could never regret anything. I couldn't look back and think to myself 'maybe if I looked after him myself he might have been able to walk.' I have given him every opportunity I possibly could, you know, by being at home he has a close relationship with his brothers and the neighbours that call in, I don't think that would be possible if I didn't care for him." (Louise)

4.2.1.2 Spousal relationships

Similarly, love and duty was regarded as the main reason to care to care for a spouse. The marriage vows, "*in sickness and in health*" were quoted throughout the narratives.

"I signed up for it. I took those vows, to always look after her, in sickness and in health. We always knew it was a possibility. It could have been me who fell ill, and if the shoe was on the other foot, she'd do it for me." (David)

"When people get married, they take vows; they plan to live out their lives together, to grow old together. It's not ideal, but in a way it's planned for, it's what they signed up for." (Monica)

4.2.2   Repayment

With regard to caring for older individuals, participants described caring as a method of repayment for something an individual may have done for the carer previously. Interestingly in these cases, caring is viewed as a token of gratitude for whatever the care recipient had done for the carer in the past.

> *"I was sick for years, when my children were small, and I never once had to ask her for help. She was always there. She cooked dinners, cleaned, minded the kids, and looked after me. In caring for her I'm saying thank you. I think she knows that."* (Angela)

> *"She brought me up, she changed my nappies when I was a baby, sang me to sleep at night, she has listened to all my worries over the years and mopped up my tears. She has made me the person I am today. I owe her everything. Caring for her is just my small way of saying 'thank you' for everything she has done for me."* (Veronica)

4.2.3   Reluctant carers

It was noted by a number of participants that care, especially caring for older relatives is carried out increasingly as a result of there being no alternative option. The high cost of nursing homes, increased emigration and growth in the trend of the nuclear family has meant that increasingly the responsibility of care falls onto one person; individuals become reluctant carers.

> *"I see more and more people being put in the position of caring, without having a choice; no other relations live nearby, perhaps they're the only relation and the older person doesn't want to enter a nursing home, or they can't afford one."* (Judy)

> *"We promised her she'd never go into a nursing home, and I was the only person in a position to be able to care for her at home."* (Patricia)

4.3   Impact on life

All of the informants participating in this study saw caring as having a great impact on carers' lives. This impact involved aspects of life such as health, employment, and participation in social life and activities.

4.3.1. Impact on physical health

The impact of caring on the carers' physical health emerged as a key finding in this study. Several participants noted how the strenuous and challenging nature of caring impacted on their physical health, often people complained of issues such as back problems. These problems arose from, lifting or carrying an individual, or pushing non-motorised wheelchairs. Participants remarked, however that although equipment, such as hoists were available, they were either not entitled to grants for this equipment from the State, it was too expensive to buy or they had to fight to get it, and as such had to carry out their caring responsibilities without these aids for a period of time.

> *"We were told that he wasn't entitled to a motorised wheelchair, and that was ok when he was a small child, but as he got bigger it became more difficult. He got bored very easily and he'd want me to take him outside, and I'd have to push him up and down the garden. That wasn't easy. It took its toll on my back."* (Anna)

Conversely, some participants stated that although aids and equipment were available to carers, it is not always used, as lifting and/or carrying may have saved time, and this too can result in injuries and affects physical health.

> *"I never used to use the hoist; I am a reasonably big fellow and Tanya is a petite woman. I could get Tanya up using one arm and have her on or off the loo faster than hoisting her. I lifted her several times a day but after a while my back started giving me trouble."* (David)

All participants involved in this study noted feeling tired or drained as a result of their caregiving responsibilities. The demanding nature of care and long periods of time spent caring for a family member, while also balancing other aspects of life such as rearing children and household duties can leave family carers feeling weary and exhausted.

> *"I'm always on the go, from the very first thing in the morning, until last thing as night. It's very hard. It can be very tiring."* (Angela)

"I feel exhausted. At times it can be very demanding." (David)

4.3.2   Impact on mental health

The findings of this study found a strong correlation between caring and mental health issues. All participants remarked that caring had impacted in some form on their mental health. In most cases participants noted that the stress of caring impacted on them significantly. Stress often emerged as a result of dealing with time pressures, especially in the case of those responsible for caring for two generations.

> *"Small things, like dropping the kids to school, its only 10 minutes away, but that's a 20 minute return journey, and I'm always rushing back, especially in the morning if there's a doctor's appointment, or even just to make sure she hasn't fallen."* (Angela)

Stress was also caused as a result of trying to secure individuals entitlements. Participants stated that fighting for entitlements, such as aids for caring or mobility or to get hospital appointments for the person they cared for was a task that used up a lot of energy and has a tendency to cause a lot of stress.

> *"I was told that he shouldn't be so far down on the waiting list for his operation, so I had to contact this county councillor, who told me to contact a T.D., and I spent hours on the phone, being passed from one person to another, and that has happened on more than one occasion. It is exhausting."* (Louise)

> *"It feels like everything is a battle."* (Anna)

Stress was also caused as a result of the illness of individual being cared for. Carers often find themselves in demanding situations, illnesses such as Alzheimer's and Dementia can be responsible for altering the personality of the individual being cared for. People with dementia may sometimes behave

aggressively, either physically or verbally, and this can be very distressing for the carer.

> *"It can be stressful, you're caring for someone you love, but they don't even recognise you. You're looking after every element of their care and they're resisting you, making it difficult and becoming angry and lashing out."* (Patricia)

4.3.3   Impact on Employment

All participants in the study described how their caring role had impacted on their employment. The responsibility and demands associated with caring meant that employment ceased when caring began, or it stopped an individual from returning to work. Some participants remarked how they had lost their identity as a result of ceasing employment.

> *"Working doesn't even come into the question. There's no way I could work and look after Daniel. I worked for 27 years, but once he was born I had to stop, before that I never thought I'd give up my job for anyone or anything."* (Anna)

> *"I'm unemployable. She has a lot of medical problems. If I worked I'd just be waiting on the end of the phone, 24/4, in case something happened, if she got a temperature or whatever. Nobody would employ me or keep me in a job."* (Sarah)

4.3.4   Participation in Social Life

All participants noted that as in other aspects of life the caring role had also impacted on their social lives. Most remarked how they had 'no social life'. Participants remarked that even when they did get to socialise or get relief from their caring role, their responsibilities were so great that could not switch off, and their mind was still at home with the individual they care for.

> *"My social life completely diminished, we can't leave her with just anybody. You know, we couldn't exactly get in a teenage babysitter to look after her, the way you would with other children."* (Sarah)

"I've gone out before, and I know she's in good hands, but I'm always thinking I hope they've done 'x' the way I've told them to, or I hope they've given her the right tablets. My mind is always there." (Patricia)

"I'm just on standby all of the time." (Anna)

4.3.5 Isolation and lack of freedom

All of the participants who provided care described having feelings of isolation and a lack of freedom in their lives. Participants regularly experienced these feelings, which stemmed from the difficult nature of care. Participants explained that their lives existed around that of the person they care for and how every decision they made was based on the situation of the care recipient.

"You know, sometimes it feels like everyone else's lives are moving on around me. And it's almost like my life has stood still. I feel like I exist only to look after someone else. It can be lonesome." (Angela)

"Sometimes I feel my own time is running out. I'm getting older. I wonder if I'll get the time to do the things I want to do. Will there be any time left over for me." (David)

"It's almost like your freedom is gone. You can't really do anything else. The choices have gone out of your life; you're no longer free to do the things you want to do. You know, even small things like doing a weekly shop, turn into big things. You've got to make sure that somebody will be there to make sure everything is alright while you do whatever you need to do. Your time is totally curtailed. Anything I want to do, it all has to be pre-planned around my Mum." (Veronica)

4.4 Supports for carers

All carers in this study received some formal or informal support in their caring role. Participants testified as to the importance of supports to enable them to carry out their caring roles to the best of their abilities.

4.4.1 Informal support

All of the carers who participated in this study received some type of informal support. Most often informal support occurred in the form of help and respite from mutual relatives, friends and neighbours of the carer and care recipient. Participants noted how this was vital in enabling them to care for an individual to the best of their abilities, as it gave the carer a break from their caring and allowed them to refresh. Additionally, informal support allowed carers to carry out tasks necessary to their caring role, such as grocery shopping and collecting medications.

> *"I don't know what I'd do without my sister and my neighbours. They're so good, my sister comes over and stays most Saturday and Sundays and if I ever need my neighbours to stay with Mum for an hour they're very obliging. It's great; it gives me the opportunity to get bits and pieces done." (*Patricia)

However, some carers caring for a parent noted that at the beginning of their caring role other family members were very supportive and willing to help with the care, but as time went by the amount of help given by other family members began to dwindle.

> *"At the start it was great, you know, my brothers-in-law or my sister-in-law would come to stay at the weekend to give me a break. But as time has passed that has stopped. They might call once a month for a few hours."* (Angela)

4.4.2 Formal support

All interviewees viewed formal support as essential in enabling carers to care and to meet the needs of the individuals they care for. All participants believed that carers should be financially supported for the role which they carry out.

> *"The State should absolutely support carers; you know its costs tens of thousands to care for one person in a residential care home. We provide*

24/7 hour care at home, to the very best of our abilities and save them money. We should be compensated in some way to help us care." (Sarah)

Most of the participants who were carers received formal support. This support came in the form of Carer's Allowance or Carer's Benefit and home help. Participants regarded these State supports as crucial to their caring. For several carers the Carer's Allowance and Carer's Benefit went back into caring for the individual. However, two of the carers participating in this study did not qualify for any supports other than 30 minutes of home help a week. In both cases there was a family farm attached to the participant, as the farm was regarded as an asset it meant these participants did not qualify for Carer's Allowance or Carer's Benefit.

"I don't get the Carer's Allowance, I don't qualify for it. As I'm self employed as a farmer I have land, the land is deemed to be an asset. I accept that it is an asset, but it just exists. It doesn't make money if I don't work on it. They don't take into account that because I'm caring, I can't work the land." (Veronica)

4.4.3   Support from organisations

Two participants received home respite care from carer support organisations. However in both cases these carers cared for children and although they found this support beneficial they remarked on how child protection procedures disallowed them from leaving the house while a support worker was there. These carers remarked that as a result they got almost the same work done as when they were on their own.

"Don't get me wrong, I totally understand why child protection procedures are in place, but because I can't leave Daniel alone I just don't get what I should from the home respite." (Anna)

4.5   Positive aspects of providing care

All participants in this study described positive aspects of caring for a family member. These positive elements ranged from the close relationship which develops between the carer and the individual in need of care; to the close relationships between the family of the carer and the person being cared for; to reassurance for the carer that they have done everything they possibly can for the individual in need of care and the creation of memories.

4.5.1   Close relationship between carer and care recipient

All participants spoke of the close relationship between the carer and the care recipient. Often these relationships were strong at the commencement of caring, but in caring individuals believed that relationships were strengthened further, this was especially apparent in the cases of children caring for elderly parents. The demanding nature of care, its intensity and intimacy means that carers spend long periods of time carrying out a multitude of tasks for the person in need of care.

> *"We were always close, but I think in the last few years we've grown closer. She doesn't get out as much as she used to, so I'm the one that tells her the news and the gossip. Every morning, after I drop the kids to school I make a cup of tea and sit down beside her in the bed and have a good old gossip. I know that wouldn't happen if I wasn't looking after her."* (Angela)

> *"A special bond comes with care, created by the actual care you give to the person and I think you can only get it from caring for somebody. It's something I'll treasure forever."* (Patricia)

4.5.2   Close Relationships with carer's families and care recipient

Numerous participants noted the close bond which develops between the person being cared for and the families of the carer. In each case participants described how relationships had developed and strengthened as a result of the

care being provided to family member. Several participants noted that these types of bonds and relationships would not be possible if the individual was cared for in a nursing home or residential home. Again, the nature of care enabled strong bonds to become established and bolstered.

"He's so close to his brothers, and they've adored him from the very minute we brought him home from the hospital. They'd spend hours trying to entertain him, they'd play music for him and his face would just light up. Even today, they come home from college on a Friday evening and his face still lights up." (Anna)

"She's so close to my children, because we live with her and care for her. I'm so proud of them, they do so much for her, they're very close to her." (Angela)

4.5.3 Reassurance

Several participants spoke of the fact that in providing care for a family member they are reassured that they have done everything they possibly could for that individual. Participants commented that they would never have any regrets that they did not spend time in helping the individual in their time of need, and also how they would not have any guilt, as they will always be assured that they did the best they could for the person in need of care.

"I will always know that I did the best I possibly could. I'll never have to say 'Oh, what if I had done this? Or what if I had done that?' Because I'll have done everything I could." (Angela)

"By looking after him, at home, at least I knew that I would give him every opportunity I possibly could. I could never regret anything." (Anna)

4.5.4 Creation of memories

Many of the participants in this study commented on the memories created as a result of caring. Due to the intensity of caring and long periods of time spent

with the individual in need of care carers have greater opportunity to create meaningful memories with the person needing care. Several of the carers also noted that this may not be possible if the individual was cared for formally.

> *"Lovely memories can be created through caring. She loves classical music, and I always have it playing for her on the radio or the TV . . . one day she called me out of the kitchen and said 'will you dance with me?' and she had never done that before. There I was dancing around my sitting room at lunchtime on a Tuesday. It upset me at the time, it was so sad and surreal, but it's a memory I'll always hold dear to my heart."* (Patricia)

Memories were also created with other family members, especially close family members of the carer.

> *"There was one night . . . I woke up, it was about 2 o'clock in the morning and all I heard was giggling and laughing. So I got up to see what was going on. There was a light on in my mother-in-laws room and when I went in the kids were sitting around her telling stories and having a great laugh. It was just so lovely. It's such a lovely memory for them, and me to have."* (Angela)

4.6   Conclusion

This concludes main findings of the present study, which highlighted the most significant experiences of the seven carers and two carer support workers interviewed. These findings correlated to the motivation to care, the impact caring has on various aspects of life and the supports available to carers. The findings also highlighted the positive aspects related to caring for a family member. Although these findings cannot be generalised, they do provide for a greater conceptualisation of the participants' experiences of providing care for a family member and present some important issues, which will be addressed in the subsequent chapter.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1   Introduction

This study set out to obtain the views and experiences, at first hand, of individuals who provide care for family members. This chapter will consider the findings of the current study and contemplate these findings with reference to previous research, in order to highlight the main factors contributing to the experience of family carers and the impact caregiving has on their lives.

5.2   Theoretical framework

The findings of this study bear many comparisons to the conditions Pearlin *et al.* (1990) identify as being associated with stress. Pearlin *et al.* (1990) examine the interrelationship between socioeconomic background and stressors such as the demands of the caregiving role, direct hardships experienced by the carer and tension between roles, involving endeavours separate to the caregiving role such as conflict with employment, economic problems, restriction of social life, loss of self and freedom. Pearlin *et al.* (1990) outline outcomes for carers such as anxiety, cognitive disturbance and negative impact on physical health. However, as Quinn *et al.* (2010) discuss, this model fails to take into account the positive aspects associated with providing care, such as the close bonds forged through caregiving, the creation of memories and the gaining of reassurance, as found in the present study.

5.3   Motivation to provide care

The participants consistently discussed their experiences of caring in terms of their motivation to care for family members. The findings confirmed a prominent correlation between the motivation to care and the experience of the carer. This finding is consistent with many authors' views that positive caring experiences are conditional to positive motivations (Lyonette & Yardley, 2003; Romero-Morena *et al.*, 2010; Smebye & Kirkevold, 2013). Similarly, Camden *et al.* (2011) found that an individual's motivation to provide care is more significantly related to the quality of the relationship with the care

recipient, than any other factor. The next section will discuss the motivations to provide care in further detail.

5.3.1 Relationship between carer and care recipient

The present study found that factors such as the nature and quality of the relationship between the carer and care recipient acted as strong motivators in providing care. Participants regarded caring as being a part of their role. In the case of parents, caring for a child, it was understood as part of their parental responsibility, while in the case of spouses it was an element of the contract of marriage. In this study, this type of motivator was regarded as positive by the participants who cited it, this is similar to the findings of Camden *et al.* (2011) who found that motivators such as these were positive, which in turn meant the carer has a positive experience of caring. However, Lyonette & Yardley (2003) found that providing care due to obligation, duty or responsibility was associated with higher levers of carer stress and negative experience of caring. Romero-Moreno *et al.* (2010) similarly found that Dementia carers who reported few intrinsic motives and more extrinsic motives were at particular risk for negative caregiving outcomes. As, Kietzman *et al.* (2013) established, carers who were motivated by close family relationships and the specific needs of the care recipient are most likely to find value in the caregiving role.

5.3.2 Reluctant carers

A number of participants noted that often carers provide care due to a lack of choice. Changing demographics and economic factors have meant that often the responsibility of care falls onto one person, forcing the individual to become a carer. In reluctant caring relationships, family carers were unenthusiastic about taking on the caring role, being largely motivated by a sense of duty and obligation, rather than love and affection, as Patricia stated:

"We promised her she'd never go into a nursing home, and I was the only person in a position to be able to care for her at home."

The participants' experiences of reluctant caring is in keeping with the findings of Smebye & Kirkevold (2013), Lyonette & Yardley (2003) and Camden *et al.* (2011); living up to cultural values and societal expectations was important to reluctant carers, and as such providing care as a result of guilt, duty, responsibility, the perceived disapproval of others if they do not take on the caring role and an overall lack of choice. The perception of such external pressures to care is in turn associated with a largely negative experience of caring. This is consistent with the findings of Romero-Moreno *et al.* (2011), who found that those who perceive having more choice in adopting the position of caregiver, experience greater levels of general wellbeing.

5.4   Impact on life

All of the participants participating in this study saw caring as having a substantial impact on aspects of life such as physical and mental health, employment and income, and on social life and participation in activities, this is consistent with findings from Pinquart & Sorensen (2007), O'Brien (2009), O'Sullivan (2008) and Colombo *et al.* (2011). The impact which caring had on the various aspects of life will be further discussed below.

5.4.1.   Impact on physical health

The experience of caring, especially caring for a long period of time was found to be associated with physical health issues. These physical health issues range from back and neck injury, to tiredness and lack of energy. This is consistent with the findings from O'Brien (2009) who reviewed family carers' health and found that due to the strenuous and demanding nature of care provision, over half of the participants in his study described having a medical problem; this was most frequently a back injury. Similarly, Edwards *et al.*

(2008) found that poor health among carers may relate to physical and other injuries caused by caring, rather than being related to the ageing process.

Although the carers participating in this study rated their health as being good, several carers described health problems caused as a result of caring, and this finding is reflected in the findings of the Carers Scotland (2011) study, which indicated that over half of participants who described their health as 'good' also gave details of long term illnesses or disabilities, with conditions either commencing or worsening after care provision began.

5.4.2 Impact on mental health

There was found to be a strong correlation between caring and mental health issues, echoing the findings of many authors (Pinquart & Sorenson, 2004; Cummins *et al.,* 2007; Stokes, 2010; Colombo *et al.,* 2011). All participants perceived that caring had impacted in some manner on their mental health, particularly in relation to stress. Sandwich generation carers remarked on the stress caused by time pressures and caring for two generations; parents and children[1]. This reiterates the findings of McGarrigle & Kenny, (2013) who ascertained that two-thirds of women who provide help to their children are also providing informal care to their parents. McGarrigle & Kenny (2013) also found that there was a relationship between providing care and depression, hypothesising that this may be as a result of the stress of delivering care, to both parents and children, exhausting both time and finances.

Stress was also caused as a result of trying to secure individuals entitlements, such as aids for caring or mobility or to obtain hospital appointments for the care recipient. Participants described these events as happening frequently, especially where the care recipients illness or disability

---

[1] Kenny & McGarrigle (2013, p. 3) define sandwich carers as "women aged 50-69 years with both a living parent and children within the last two years."

was substantial or where their health was deteriorating. As Nerenberg (2008), Dale *et al*. (2008) and Lee *et al.* (2012) discuss, as an individual's health deteriorates, the demands on the carer escalate and may reach a perilous level, with the carer experiencing severe stress or burden. In these cases fighting to secure entitlements consumes the carer's energy further and has a tendency to cause additional stress to the carer. Similarly, Stirling *et al.* (2010) argue that due to the particularly challenging caring circumstances, even minor care recipient demands may cause tremendous stress for carers.

Stress was also caused as a result of the illness of the individual being cared for. Participants spoke of demanding situations, as a result of caring for a person with specific illnesses, such as Alzheimer's or Dementia which can be responsible for altering the personality of the individual. People with Dementia may sometimes behave aggressively, either physically or verbally, and this can be very distressing for the carer. One participant spoke of severe stress as a result of caring for an individual who had a tendency to lash out, both verbally and physically due to their illness. This correlates to research carried out by Cooper *et al*. (2010), who investigated abusive behaviours experienced by family carers of people with Dementia, and found that almost half of carers recounted that the care recipient was abusive in the previous months and more than one third of the sample reported that the individual being cared for was abusive '*at least sometimes'*. Similarly, Burton *et al.* (2003) found that caregivers described negative health effects, especially when providing on-going care or when transitioning to tremendously challenging physical and emotional care-giving, for example in cases where the care recipient had a condition such as Dementia. Consistent with this, in their meta-analysis Pinquart & Sorenson (2004), found that studies of carers who provided care to people with Dementia recounted the highest levels of stress and greatest loss in psychological wellbeing.

5.4.3 Impact on employment

The employment opportunities of each caring participant in this study had been negatively impacted by providing care to a family member. All participants commented on how their caring role had impacted on their employment. The substantial responsibility and demands related to caring necessitated that employment ceased when caring began, or it stopped an individual from returning to work. Participants believed that in order to provide the care which the care recipients required, they would not be able to continue in their employment alongside this. This is similar to the findings of Edwards *et al.* (2008) who found that almost half of female carers who were not employed at the time of the interview were employed just prior to commencing their caring role.

Participants also believed even if they had remained in employment or returned to employment, the demands of their caring role would impact negatively on their employment; "*nobody would employ me or keep me in a job.*" This corresponds to the findings of Stiell *et al.* (2006) who found that most parent carers stated that caregiving had a negative effect on their own employment, involving a negative impact on relationships with colleagues and a belief that opportunities of advancement were refused employees with caring responsibilities.

5.4.4 Impact on social participation

All participants noted that the demands of their caring role had affected their social lives. Several participants stated that they had '*no social life*'. This is comparable to Saunders (2011) findings; in this study participants outlined the demanding nature of their caring role and the manner in which it disconnects them from previous social networks. Over half of carers categorised their social life as non-existent, very little or limited to the monthly carer support group meetings. Furthermore, many carers do not have access to supports to

allow them have respite from their caring obligations to enjoy a social life, this is similar to findings from The Carers Association (2008), and was especially visible in this statement from one participant

> *"My social life is completely diminished; we can't leave her with just anybody. You know, we couldn't exactly get in a teenage babysitter to look after her, the way you would with other children."* (Sarah).

5.4.4.1   Social isolation

Participants who provided care described suffering feelings of isolation and a lack of freedom in their lives. Family carers also described the all-encompassing nature of care; family carers often provide such high levels of care that they feel it has taken over their lives, it devours a large amount of their time and all decisions they make are based on the care recipient. This culminates in family carers feeling that they have no freedom in their lives any longer. This is comparable to the findings of Stoltz *et al.* (2003), who discuss how, as caring intensifies this can result in feelings of frustration and sacrifice of self among family carers, many family carers experienced a lack of freedom and they felt that they had no life anymore. Similarly, Orpin *et al.* (2014) found that often any needs the carer may have are often placed on hold for some distant time in the future.

5.5   Supports for carers

All caring participants in this study received formal or informal support, or a combination of both in their caring role, this is reflects the findings of Henwood & Hudson (2008) and Yeandle & Buckner (2007). Each participant affirmed the value of these supports, as they enable them to perform their caring roles to the best of their abilities.

5.5.1 Informal support

All of the carers who participated in this study received some type of informal support, this frequently emanated in the form of help and respite from mutual relatives, friends and neighbours of the carer and individual being cared for. Support such at this allowed carers to perform their role to the best of their abilities, as in some cases it enabled carers to take a break from their caring, while in other cases it assisted carers to carry out further tasks linked to their caring role. This is consistent with the findings of Cecil *et al.* (2012) Okabayashi *et al.* (2008) and Arai *et al.* (2004) who found that carers who receive temporary respite and support report lower levels of burden.

However, in some cases carers noted that as the length of time spent caring increased the support from family members decreased, often causing stress frustration and feelings of isolation to the carer. This resembles the findings of Cecil *et al.* (2012), who discuss how some participants in their study received more family support in the early stages of caring than in the long-term. Similarly, Yeh & Bull (2012) indicate significant associations between lack of family support and caregiver burden.

5.5.2 Formal support

All interviewees viewed formal support as essential in enabling carers to care and to meet the needs of the individuals they care for. All participants believed that carers should be financially supported for the role which they carry out. However, some participants received only minor formal support (30 minutes of home help per week). This is as a result of means testing of formal supports; these particular participants did not receive support due to the existence of a family farm. Conversely, these participants were unable to make full use of these assets due to the demands of caring; the duration of time spent caring for a family member meant that they were unable to work full-time on the farm. This demonstrates, as Henwood & Hudson (2008) argue, the way in

which individuals often find themselves screened out of the formal process. In failing to take situations like this into account the Government are failing in their efforts

> "*to ensure that carers feel valued and supported to manage their caring responsibilities with confidence and empowered to have a life of their own outside of caring.*" (Department of Health 2012, p.3).

5.6   Positive aspects of providing care

All participants in this study described positive aspects of caring for a family member. These positive elements varied from the close relationship involving the carer, the carer's family and the care recipient, especially through the creation of memories and a sense of reassurance to the carer that they have done their utmost for the individual in need of care. Wolff *et al.* (2007), Hales (2007) and Hughes (2007) reported similar outcomes. Overall, six of the seven participants who provided care to a family member considered caring to be a positive experience; this is comparable to Kolmer *et al.* (2008), who observed that although carers report stress and joy in relation to providing care, they describe to some extent more joy than stress.

5.6.1   Close relationship between carer, carer's family and care recipient

All participants referred to the close relationship between the carer and the care recipient. Often these relationships were strong before caring began, but participants believed that relationships were bolstered as a result of caring, this was particularly evident in the cases of children caring for elderly parents. The challenging nature of care, its intensity and intimacy means that carers spend long periods of time carrying out a multitude of tasks for the care recipient. Often the carer is a vital connection for the care recipient to the wider community, as they convey the local news and gossip, encouraging relationships to grow closer. This is in keeping with the findings of Cohen *et al.* (2002) who established that one of the fundamental positive traits related to caring was that of companionship. In the same way Lopez *et al.* (2005) discuss

how carers explained the way in which caring brought them closer to their loved ones and gave meaning to their existence.

Similarly, participants remarked on the close bonds which develop between the care recipient and the families of the carer. Participants considered these types of relationship to have grown and intensified due to the provision of care, often these relationships would not be possible if the individual was not cared for by a family member. In one case, the care recipient moved into the family home of the carer. The carer discussed how this enabled the care recipient to become closer to her grandchildren, she acknowledged that this type of relationship would not have been possible if she was cared for in a nursing home, or if she did not require care. This finding is consistent to that of Packenham (2005), who found a growth in family relations between the family and the care recipient due to caring. Packenham (2005) also found that care recipients use family relations as a source of meaning of purpose and wellbeing.

Often these close bonds between carers, their family and the care recipient are bolstered through the creation of memories, which would not be possible if the individual was cared for formally. The intensity of caring and duration of time spent with the care recipient allow carers greater opportunity to create memories with the individual. One participant who cared for her mother who had Dementia, explained that due to the length of time she spends caring for her often she witnesses periods where her mother is completely lucid,

> *"Sometimes she can be so lucid, and we chat away for maybe an hour or so, just like we used to."*

This finding is reflected in that of Normann, Henriksen, Noberg & Asplund (2005), who reflect that in periods of lucidity a person with Dementia, can reveal their personhood and relationships are strengthened.

5.6.2 Reassurance

Some participants discussed how providing care to a family member gave them reassurance that they have done everything they conceivably could for the individual. Participants expressed that they would never have any regrets or guilt about helping the individual in their time of need, they will always be certain they did the best they could for the care recipient. This reiterates the findings of Quinn *et al.* (2010), who note that providing care gives carers a sense of fulfilment and contentment that they are helping the person in need of care, while also keeping the individual out of a nursing home. Cohen *et al.* (2002) reiterate these findings, as they found carers listed positive aspects of care as fulfilment, reward, enjoyment, and the satisfaction of meeting an obligation and providing quality of life to a loved one.

5.7   Limitations

This was a small-scale study and as such the findings cannot be considered representative of the general family carer's experience. The study also relied on the accounts of participants who were in contact with, and received support from various caring organisations, consequently the participants experiences may differ from those who provide care without receiving this support. A third limitation of this study pertains to the fact that data collection took place over the Summer months, a time when various respite supports and day-care centres take summer holidays. As a result, this study excluded potential participants who were unable to take part in this study due to increased care demands while these services were unavailable. Finally this study includes only one male participant's experience of caring, thus the male experience of

caring provided in this study is limited and it cannot be considered to be gender representative.

5.8   Conclusion

This study sought to explore the experience of individual caring for a family member and the impact this role has on their lives. The discussion shows that the findings provide an insight into the diverse experiences of family carers. Despite the variety of these experiences, common themes emerged which revealed that family caring can be motivated by many different factors, and it can present substantial challenges, such as difficulties relating to both physical and mental health, employment and social participation. Inconsistencies between the objectives of social policy and the outcomes of income supports and formal support services were observed. The findings also highlighted that for some participants providing care to a family member may have positively enriched their lives, through forming close relationships with family members and having a sense of reassurance. The following chapter makes recommendations and draws a conclusion to this study.

CHAPTER SIX: CONCLUSION

6.1   Introduction

This chapter concludes the present study. It describes the key considerations which developed from the findings of this study, as portrayed in chapter four. Though this was a small scale study, the findings are noteworthy, as six of the seven family carers interviewed, described their caring experience as positive. This is a significant empirical finding, in view of the prevailing emphasis on the negative impacts of caregiving.

A key finding was the close relationships which caregiving fostered, between the care recipients and the caregiver and also the caregivers family. However, the findings also demonstrated substantial difficulties were also attached to caregivers' experiences. These difficulties related to issues of employment, physical and mental health, social participation and support. These findings both supported and contradicted other findings of family carer research.

The main objective of this study was to explore the experiences of individuals providing care to a family member. The findings, which focus on these experiences, are important, as there has been little research carried out in this area from an Irish setting. This research has presented some important issues, such as the need for formal and informal support, motivations behind caring, and the difficulties and positive elements related to caring.

The incidence of family carers in Ireland is growing steadily, according to the Care Alliance (2013), and this will continue to increase if the EC's (2008) predictions are correct. Therefore there is significant need for further research, to gain a better understanding of the various experiences of family carers. The following section will briefly outline the key recommendations, which resulted from the findings of this study.

6.2   Recommendations

It is recommended that family carer research is furthered, to develop a more comprehensive understanding of the mechanisms and processes inherent in providing care to a family member and how these impact upon the experience of a carer. It is essential that this research is completed within the Irish context, to support family carers to cope with the stressors and challenges of caring for a family member.

Healthcare professionals should not only consider the health and wellbeing of individuals being cared for in the community, but they should also be aware of the health and wellbeing of their carers. Furthermore, family carers should be assisted by having their own physical and mental health evaluated, so as to ensure they can cope with the difficulties, associated with caregiving and to prevent risks associated with caregiving, such as stress.

One of the main findings of the present study relates to the difficulty carers encounter, particularly the stressful nature of caregiving. Therefore, energies need to be focused on interventions that can ease the amount of stress experienced by family carers. There are a variety of Carer Organisations which offer advice, information and supports to family carers across Ireland. It is vital that these organisations, who support the needs and interests of carers, continue to be supported by the State, in line with the *National Carers' Strategy* (Department of Health, 2012).

All family carers should be respected and acknowledged for the crucial, difficult and challenging work they perform, and they should be suitably rewarded (Department of Health, 2012). As summarised in the *National Carers' Strategy*, it is vital that income support payments, remain available to eligible carers, so that carers do not become additionally burdened (Department of Health, 2012).

It was noted that an increasing number of carers provide care to a family member because there is no alternative. It is vital that more research is conducted into reluctant carers, to establish the incidence, and impact of this type of caring on the carer.

The majority of research that has been conducted in the area of family caring concentrates on the negative impact of caregiving on the carer. However, the present research found that participants described many positive elements relating to caregiving. Future research should further examine the positive consequences of providing care to a family member.

REFERENCES

Adams, K.B. (2007). Specific effects of caring for a spouse with dementia: differences in depressive symptoms between caregiver and non-caregiver spouses. *International Psychogeriatrics, 20(3), 508-520.*

Arai, Y., Kumamoto, K., Washio, M., Uda, T., Miura, H. and Kudo, K. (2004). Factors related to feelings of burden among caregivers looking after impaired elderly in Japan under the Long-Term Care insurance system. *Psychiatry and Clinical NeuroSciences, 58(4), 396–402.*

Australian Bureau of Statistics. (2004). *Disability, ageing and carers, Australia: Summary of findings, 2003.* Canberra: Australian Bureau of Statistics (http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/3319EC785921CFFCCA2577FA0011C3C8?opendocument).

Barrett, A., Savva, G., Timonen, V. and Kenny R.A. (2011). *Fifty plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA).* Dublin: Trinity College Dublin.

Bertrand, R.M., Fredman, L and Saczynski, J. (2006). Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *Journal of Ageing and Health, 18(4), 534-551.*

Bryman, A. (2012). *Social Research Methods.* Oxford: Oxford University Press.

Burton, L.C., Zdaniuk, B., Schulz, R., Jackson, S. and Hirsch, C. (2003). Transitions in Spousal Caregiving. *The Gerontologist*, 43(2), 230–241.

Camden, A., Livingston, G. and Cooper, C. (2011). Reasons why family members become carers and the outcome for the person with dementia: results from the CARD study. *International Psychogeriatrics*, 23(9), 1442–1450.

Care Alliance. (2013). *Family Caring in Ireland.* Dublin: Care Alliance (http://www.carealliance.ie/userfiles/file/Report%202013%20FA%20130513.pdf).

Carers Scotland. (2007). *Sick, Tired and Caring: The impact of unpaid caring on health and long term conditions.* Scotland: Carers Scotland.

Cecil, R., Thompson, K., Parahoo, K. and McCaughan, E. (2012). Towards an understanding of the lives of families affected by stroke: a qualitative study of home carers. *Journal of Advanced Nursing*, 69(8), 1761-70.

Central Statistics Office. (2010). *Quarterly National Household Survey (Quarter 3, 2009)*. Dublin: Central Statistics Office (http://www.cso.ie/en/media/csoie/releasespublications/documents/labourmarket/2009/carersq32009.pdf).

Cohen, C.A., Colantonio, A. and Vernich, L. (2002) Positive aspects of caregiving: rounding out the caregiver experience. *International Journal of Geriatric Psychology*, 17(2), 184-188.

Colombo, F., Llena-Nozal, A., Mercier, J. and Tjadens, F. (2011). *Help Wanted: Providing and paying for long-term care.* Paris: OECD Publishing. DOI: 10.1787/9789264097759-en.

Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R. and Livingston, G. (2010). The determinants of family carers abusive behaviour to people with dementia: results of the CARD study. *Journal of Affective Disorders*, 121,136-142.

Creswell, J. (2009). *Research design: qualitative, quantitative, and mixed methods approaches.* London: Sage Publications.

Cummins, R.A., Hughes, J., Tomyn, A., Gibson, A., Woerner, J., and Lai, L. (2007). *Australian Unity Wellbeing Index Survey: 17.1. The wellbeing of Australians: Carer health and wellbeing.* Melbourne: Deakin University, Carers Australia and Australian Unity.

Dale, B., Sævareid, H.I., Kirkevold, M. and Söderhamn, O. (2008) Formal and informal care in relation to activities of daily living and self-perceived health among older care-dependent individuals in Norway. *International Journal of Older People Nursing,* 3(3), 194-203.

de Boer, A.H., Broese van Groenou, M. And Timmermans, T.J.M. (2009). *Mantelzorg. Een Overzicht van de Steun van en aan Mantelzorgers.* The Hague: Social and Cultural Planning Office.

Denscombe, M. (2010). *The good research guide: For small scale social research Projects.* Maidenhead: Open University Press.

Department of Health. (2012). *The National Carers' Strategy: Recognised, supported, empowered.* Dublin: The Stationary Office.

Department of Social Protection. (2014). *Carer's Allowance*. Dublin: Department of Social Protection (http://www.welfare.ie/en/Pages/ca.aspx).

Donelan, K., Hill, C., Hoffman, C., Scoles, K., Hollander Feldman, P., Levine, C., *et al*. (2002). Challenged to care: informal caregivers in a changing health system. *Health Affairs*, 21, 222–231.

Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N. and Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia.* Austraia: Australian Institute of Family Studies (http://www.aifs.gov.au/institute/pubs/resreport16/report16pdf/16.pdf).

European Commission (2008). *Long-term Care in the European Union.* Luxembourg: Office for Official Publications of the European Communities.

Fahey, T. and Fields, C.A. (2008) *Families in Ireland: An analysis of patterns and trends*. Dublin: The Stationary Office.

Glendinning, C., Tjadens, F., Arskey, H., Moreé, M., Moran, N. and Nies, H. (2009). *Care Provision within Families and its Socio-Economic Impact on Care Providers*. York: University of York Social Policy Research Unit.

Government of Ireland. (2007). *National Action Plan for Social Inclusion 2007-2016*. Dublin: Stationery Office.

Green, S. (2007). ''We're tired, not sad'': benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64, 150-163.

Guthrie, G. (2010). *Basic research methods: an entry to social science research.* London: Sage Publications.

Hales, C. (2007). Crisis or commotion: An objective look at evidence on caregiving in families. *Family Matters*, 76, 18–23.

Health Service Executive. (2013). *Home Care Packages*. Dublin: HSE (http://www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/homecarepackages).

Henwood, M. and Hudson, R. (2008) Lost to the System? The Impact of Fair Access to Care. London: Commission for Social Care Inspection (http://www.melaniehenwood.com/perch/resources/cscifacslosttothesystem.pdf).

Ho, B., Friedman, J., Rappolt, S. and Noh, S. (2003). Caregiving for relatives with Alzheimer's disease: feelings of Chinese-Canadian women. *Journal of Ageing Studies,* 17, 301-321.

Hughes, J. (2007). Caring for carers: The financial strain of caring. *Family Matters,* 76, 32–33.

Hynes, G., Stokes, A. and McCarron, M. Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience. *Journal of Clinical Nursing,* 21, 1068 – 1077.

Jokinen, N. S., and Brown, R. I. (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research,* 49(10), 789–793.

Kamiya, Y., Murphy, C., Savva, G. and Timonen, V. (2012). *Profile of community dwelling older people with disability and their caregivers in Ireland.* Dublin: Trinity College Dublin.

Kiely, G. (1999). The Family and Social Policy. In Kiely, G., O'Donnell, A., Kennedy, P., and Quin, S. (Eds.), *Irish Social Policy in Context* (pp.254-268). Dublin: University College Dublin Press.

Kietzman, K.G., Benjamin, A.E. and Matthias, R.E. (2013). Whose choice? Self-Determination and the Motivations of Paid Family and Friend Caregivers. *Journal of Comparative Family Studies*, 44(4), 519-540.

Kolmer, D.B., Tellings, A., Gelissen, J.,Garretsen, H. and Bongers, I. (2008). A view from inside the family – long-term caregiving: ranked motives of long-term care providing family caregivers. *Scandinavian Journal of Caring Science*, 22, 29-39.

Kramer, B. J. (1997). Gain in the caregiving experience. Where are we? What next? *The Gerontologist*, 37, 218–232.

Lafferty, A., Fealy, G., Downes, C. and Drennan, J. (2014). *Family Carers of Older people: Results of a National Survey of Stress, Conflict and Coping.* University College Dublin: National Centre for the Protection of Older People.

Lee, D.R., McKeith, I., Mosimann, U., Ghosh-Nodyal, A. and Thomas, A.J. (2012). Examining carer stress in dementia: The role of subtype diagnosis and neuropsychiatric symptoms. *International Journal of Geriatric Psychiatry*, 28(2), 135–141.

Lee, M. and Kolomer, S. (2005). Caregiver burden, dementia, and elder abuse in South Korea. *Journal of Elder Abuse and Neglect*, 17(1), 61–74.

Lopez, J., Lopex-Arrieta, J. and Crespo, M. (2005). Factors associated with the positive impact of caring for the elderly and dependent relatives. *Archives of Gerontology and Geriatrics*, 41(1), 81-94.

Lyonette, C. and Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing and Society*, 23, 487–506.

Marshall, C. and Rossman, C.B. (2006). *Designing qualitative research.* London: Sage.

Marshall, C.E., Benton, D. and Brazier, J.M. (2000). Elder abuse: Using clinical tools to identify clues of mistreatment. *Geriatrics,* 55(2), 45–53.

McGarrigle, C. and Kenny, R.A. (2013). *Profile of the Sandwich Generation and intergenerational transfers in Ireland.* Dublin: Trinity College Dublin (http://tilda.tcd.ie/assets/pdf/intergenerational_transfers.pdf).

Nerenberg, L. (2008) *Elder abuse prevention: Emerging trends and promising strategies.* New York: Springer Publishing Company.

Normann, H.K., Henriksen, N., Norberg, A. and Asplund, K. (2005) Lucidity in a woman with severe Dementia related to conversation. A case study. *Journal of Clinical Nursing,* 14(7), 891-896.

O'Brien, F. (2008). *Family Carers Health Survey*. Tullamore: Carers Association.

Okabayashi, H., Sugisawa., H, Takanashi, K., Nakatani, Y., Sugihara, Y. and Hougham, G.W. (2008). A longitudinal study of coping and burnout among Japanese family caregivers of frail elders. *Aging & Mental Health*, 12, 434–443.

O'Reilly, D., Connolly, S., Rosato, M. and Patterson, C. (2008). Is caring associated with an increased risk of mortality? A longitudinal study of 162,884 carers. *Social Science and Medicine*, 67(8), 1282-1290.

Orpin, P., Stirling, C., Hetherington, S. and Robinson, A. (2014). Rural dementia carers: formal and informal sources of support. *Ageing and Society*, 34, 185-208.

O'Sullivan, L. (2008). *Health and Well-being of Family Carers in Ireland: results of a survey of recipients of the Carer's Allowance*. Dublin: Combat Poverty Agency.

Packenham, K.I. (2005). The positive impact of multiple sclerosis (MS) on carers: Associations between carer benefit finding and positive and negative adjustment domains. *Disability and Rehabilitation*, 27(17): 985 – 997.

Pearlin, L., Mullan, J., Semple, S. and Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30 (5), 583-594.

Pinquart, M. and Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging,* 18(2), 250–267.

Pinquart, M. and Sorensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging and Mental Health*, 8(5), 438–449.

Pinquart, M. and Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta- analysis. *Journal of Gerontology: Series B. Psychological Science and Social Science,* 62(2), 126–137.

Quinn, C., Clare, L. and Woods, R.T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *International Psychogeriatrics,* 22(1), 43–55.

Romero-Moreno, R., Marquez-Gonzalez, M., Losada, L. and Lopez, J. (2010). Motives for caring: relationship to stress and coping dimensions. *International Psychogeriatrics*, 23(4), 573–582.

Ryan, R.M. and Deci, E.L. (2000). Intrinsic and extrinsic motivations: classic definitions and new directions. *Contemporary Educational Psychology,* 25, 54-67.

Sarantakos, S. (2005). *Social Research*. Basingstoke: Palgrave Macmillan.

Saunders, J. (2011). *Social Connectedness and Use of Technology amongst Older Persons and Family Carers of Older Persons in County Clare.* Clare: Caring for Carers.

Schulz, R. and Martire, L.M. (2004). Family caregiving of persons with dementia prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry,* 12 (3), 240–249.

Schulz, R. and Sherwood, P.R. (2008). Physical and Mental Health Effects of Family Caregiving. In Reinhard, S. et al (Eds.), *State of Science: Professional partners supporting family caregivers* (pp 12-26). American Journal of Nursing, (108)9 Supplement.

Schutt, R. (2009). *Investigating the Social World.* California: Pine Forge Press.

Silverman, D. (2006). *Interpreting Qualitative Data (Third Edition)*. London: Sage.

Singleton, S., Aye Maung, N., Cowie, A., Sparks, J., Bumpstead, R., Meltzer, H. (2002) *Mental Health of Carers.* London: TSO.

Smebye, K.L. and Kirkvold, M. (2013). The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study [Online]. *BioMed Central Nursing*, 12 (29). DOI: doi:10.1186/1472-6955-12-29.

Spector, J. and Tampi, R. (2005). Caregiver depression. *Annals of Long Term Care*, 13(4), 34.

Stiell, B., Shipton, L. and Yeandle, S. (2006). *Caring for Sick or Disabled Children: Parents' experiences of combining work and care*. London: Carers UK.

Stirling, C., Andrews, S., Croft, T., Vickers, J., Turner, P. and Robinson, A. (2010). Measuring dementia carers' unmet need for services - an exploratory mixed method study. *Health Services Research,* 10, 122-132.

Stokes, A. (2010). *The Caring Reality of Family Carers: An exploration of the health status of Family Carers of people with Parkinson's disease.* Dublin: Care Alliance Ireland (http://www.carealliance.ie/userfiles/file/FullReportFinal.pdf).

Stoltz, P., Uden, G. and Willman, A. (2003). Support for family carers who care for an elderly person at home – a systematic literature review. *Scandinavian Journal of Caring Science,* 18(2), 111-119.

The Carers Association. (2008). *Listen to Carers: Report on a Nation-wide Carer Consultation.* Dublin: The Carers Association (http://www.carersireland.com/userfiles/file/ListentoCarers26Feb.pdf).

Tjadens, F., Visser, G. and Sangers, S. (2008). *Family Care in Europe. The contribution of carers to long-term care especially for older people.* Utrecht: Eurocarers.

Vitaliano, P.P., Zhang, J., and Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin,* 129(6), 946–972.

Wallhagen, M.I. and Yamamoto-Mitani, N. (2006). The meaning of family caregiving in Japan and the United States: a qualitative comparative study. *Journal of Transcultural Nursing*, 17(1), 65-73.

Wolff, J., Dy, S., Frick, K., and Kasper, J. (2007). End-of-life care: findings from a national survey of informal caregivers. *Archives of Internal Medicine*, 167, 40–46.

Yeh, P. and Bull, M.J. (2012). Use of resiliency model of family stress, adjustment, and adaptation in analysis of family caregiver reaction among families of older people with congestive heart failure. *International Journal of Older People Nursing,* 7(2), 117-126.

Appendices

Appendix A: Table of participants

Name	Age	Gender	Role
Anna	48	Female	Carer: Cares for son, aged 18, who has Cerebral Palsy and Microcephaly.
Louise	55	Female	Carer: Cares for son, aged 35, who is physically disabled, suffers from multiple health conditions and chronic pain.
Sarah	45	Female	Carer: Cares for daughter, aged 18, who is physically and intellectually disabled.
Angela	49	Female	Carer: Cares for mother-in-law (87), who has multiple health conditions, such as Chronic Obstructive Pulmonary Disease, Diabetes and suffers with a Diabetic foot, she also has limited mobility.
Veronica	48	Female	Carer: Cares for her mother (74), who has Dementia.
Patricia	56	Female	Carer: Cares for her mother (79), who has asthma and limited mobility.
David	70	Male	Carer: Cares for his wife (68), who had a stroke.
Judy	55	Female	Carer support worker
Monica	35	Female	Carer support worker

Appendix B: Interview Questions for Family Carers

At the beginning of the interview the purpose of the research was detailed and the participants were given time to read the information letter and the consent form. Once the participant was content to continue and had signed the consent form, the researcher asked the succeeding questions.

1. Introduce yourself and give a brief explanation of the purpose of the research.

2. Could you tell me about your caring role?
   Who do you care for?
   What age is the person you care for?
   What is the nature of your caring role?

3. Could you tell me about an average day in your life as a Carer?

4. What motivates you in your caring role?

5. Has your caring role impacted on aspects of your life?

6. Has it impacted on employment/income?

7. Has your role as a carer has impacted on your health in any way? Can you give examples?

8. What aspects would you consider most stressful? Can you give examples?

9. Has your role as a carer impacted on your participation in social activities/social life/ time with friends and family? Can you give me examples?

10. What types of supports are available to you? Formal/State provided/HSE hours. Informal/ family friends

11. Do you get much respite from your caring role?

12. What do you believe to be the biggest challenges associated with being a carer?

13. What are the positive aspects associated with being a carer?

14. Would you describe your experience of caring as more positive or negative?

15. Are there any ways you feel you can be better supported?

16. Do you feel you should be financially supported?

17. What policy recommendations would you make to improve to experience of carers?

18. Is there anything I haven't covered that you would like to add?

Appendix C: Interview questions for family carer support workers

At the beginning of the interview the purpose of the research was detailed and the participants were given time to read the information letter and the consent form. Once the participant was content to continue and had signed the consent form, the researcher asked the succeeding questions.

1. Introduce yourself and give a brief explanation of the purpose of the research.

2. What role do you play in terms of family carers?

3. What do you find to be the main motivator for carers, to carry out their caring role?

4. Have you found the nature of the caring role to impact on how the carer experiences this role?

5. Do you think that the caring for a family member has an impact on their lives? E.g. on role employment and employment opportunities?

6. Have you found the caring role to impact on the health of carers?

7. Have you experienced the responsibility of caring to cause stress to carers? What aspects of caring cause stress?

8. Have you found that caring impacts on the participation of individuals in social activities/social life/time with friends and family? Can you give examples?

9. What kind of supports, both formal and informal is available to carers?

10. In your experience, do family carers get sufficient respite from caring?

11. What do you believe to be the biggest challenges associated with the responsibility of Caring?

12. In your experience, what are the positive aspects associated with being a Carer?

13. What policy recommendations would you make to improve to experience of Carers?

14. What is your view on financially rewarding carers? Should they receive some support for the work they do?

15. Is there anything that I haven't covered that you would like to add?

Interviewer: Could you tell me about your caring role? For example, could you tell me about the person you care and what you do for them?

Participant: ████████████████████████████████████
██
██
██
██
██
██
████████████████████████

Interviewer: Could you tell me about an average day in your life as a Carer?

Participant: ██████████████████████████████████
██
██
██
██
██
██
██
████████████████████

██
██
██
██
██
██
██
██
██████ ██████ ██████ ██████ ██ ██████ ██ ██████ ██
██
████████████████████████████████████

Interviewer: Could you tell me about that?

Participant: ██████████████████████████████████
██
██
██

[REDACTED]

Interviewer: What motivates you in your caring role?

Participant: [REDACTED]

Interviewer: Have you found your caring role has impacted on aspects of your life?

Participant: [REDACTED]

Interviewer: Has it impacted on employment or your income?

Participant: [REDACTED]

Interviewer: Have you found your role as a carer has impacted on your health in any way?

Participant: [REDACTED]

[REDACTED]

Interviewer: Would you consider caring to be stressful?

Participant: [REDACTED]

Interviewer: What aspects would you consider most stressful? Can you give an example?

Participant: [REDACTED]

Interviewer: Have you found that caring has impacted on your participation in social activities or social life?

Participant: [REDACTED]

[REDACTED]

Interviewer: So do you get much respite from your caring role?

Participant: ████████████████████████████████
██
██
██
██
██
██
██
████

██
██
██
██
██
██
████████████████████████████

Interviewer: How did that make you feel?

Participant: ████████████████████████████████
████████████████████████████████

Interviewer: Do you receive any informal support; from family or friends or otherwise?

Participant: ████████████████████████████████
██
██
██
██
██
██
██
██
██████████████████████████

Interviewer: What type of state provided supports are available to you?

Participant: ████████████████████████████████
██

[REDACTED]

Interviewer: Do you feel you should be financially supported?

Participant: [REDACTED]

Interviewer: Are there any ways you feel you can be better supported?

Participant: [REDACTED]

Interviewer: What do you believe to be the biggest challenges associated with being a carer?

[REDACTED]

Interviewer: Do you find there are any positive aspects associated with being a carer?

Participant: [REDACTED]

[REDACTED]

[REDACTED]

Interviewer: So would you describe your experience of caring as more positive or negative?

Participant: [REDACTED]

Interviewer: What policy recommendations would you make to improve to experience of carers?

Participant: [REDACTED]

Interviewer: Is there anything I haven't covered that you would like to add?

Participant: [REDACTED]

Appendix E: Email to Carer Organisations

Dear Sir / Madam,
I am undertaking a Masters Degree in Child, Family and Community Studies at the Dublin Institute of Technology and as part of my coursework I am required to conduct a piece of research. I have identified a need for research into the experiences of informal or family carers. Care work is a vital aspect of society; it enables older people and those with health difficulties or disabilities to live fuller lives, with dignity. However, care work is very demanding for those who carry it out and, time spent caring can often mean that people are excluded from participating in social and political life. For these reasons it is important to examine the experiences and the wellbeing of carers.

I am contacting you to ask if it would be possible to recruit participants for this study from your organisation. As you deal with carers, the member s of your organisation have the experience required and would provide the insights necessary to examine the wellbeing of carers.
Ideally, I would like to begin data collection on [insert date] but I am very happy to be guided by you on this.

I hope that you find the proposed project of interest and that you would be interested in working with me. Please feel free to contact me by phone (xxxx) if you have any queries. Alternatively, you may wish to contact my supervisor, Dr. Ann Marie Halpenny at xxxx, if you would like a reference or other information.

All data collected will be gathered with the informed consent of the participating individuals and participants can refuse involvement in this study with no negative consequences until the research is completed. All data collected will be treated with the utmost confidentiality and the participant will receive complete anonymity.

Sincerely,
Tara Duigenan.

Appendix F: Information letter to participants

Please read this consent document carefully before you decide to participate in this study.

My name is Tara Duigenan, I am currently undertaking a Masters Degree in Child, Family and Community Studies at the Dublin Institute of Technology. As part of my coursework I am required to complete a research dissertation and I wish to conduct an explorative study on the experiences of family carers.

Purpose of this research:
The purpose of this study is to increase our understanding of the experiences of family carers and the impact caring has on their lives. It is hoped that through a greater understanding of these experiences, that services will be better placed to support individuals and may experience difficulties and challenges in providing care for a family member. It is also important to explore the positive aspects of caregiving.

Time Required:
The research will be carried out through an interview with the researcher. This will require up to an hour of your time. This interview can be arranged at a time and place that suits you.

What is involved:
The interview will cover three main areas:
1. Motivations for providing care
2. The main challenges and difficulties for family carers
3. The positive aspects of living in a stepfamily

Confidentiality:
Your identity will be kept strictly confidential at all times. You will receive complete anonymity; your information will be assigned a code name and any personal identifiable information will be changed to protect your identity

All data collected will be gathered with the informed consent of the participating individuals and participants can refuse involvement in this study with no negative consequences until the research is completed. All data collected will be treated with the utmost confidentiality and the participant will receive complete anonymity.

Voluntary Participation:
Your participation in this study is completely voluntary. You have the right to withdraw at any time from the study with no negative consequences. You may

also refuse to answer any or all of the questions that the researcher will ask you.

My supervisor for this research is Dr. Ann Marie Halpenny. Should you have any queries about this research please feel free to contact Dr. Ann Marie Halpenny at xxxx, or the researcher at xxxx.

Thank You,
Tara Duigenan.

Appendix G: Consent form

Researcher's Name: TARA DUIGENAN	Title: MS
Faculty/School/Department: School of Languages, Law and Social Sciences	
Title of Study: An Exploration of the experiences of individuals caring for a family member and the impact this role has on their lives	
To be completed by the interviewee (*delete as necessary*)	

3.1 Have you been fully informed/read the information sheet about this study?   YES/NO

3.2 Have you had an opportunity to ask questions and discuss this study?   YES/NO

3.3. Have you received satisfactory answers to all your questions?   YES/NO

3.4 Have you received enough information about this study and any associated health and
      safety implications if applicable?   YES/NO

3.5 Do you understand that you are free to withdraw from this study?

- at any time
- without giving a reason for withdrawing
- without affecting your future relationship with the Institute   YES/NO

3.6 Do you agree to take part in this study the results of which are likely to be published?
      YES/NO

3.7 Have you been informed that this consent form shall be kept in the confidence
      of the researcher?   YES/NO

Signed_____   Date _____

Name in Block Letters _____

Signature of Researcher _____   Date _____