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Caring for the Elderly – Identity Transitions in Informal Carers

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by

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<u>Abstract</u>

Population demographics in the UK are changing, with an increased number of elderly and infirm individuals which is expected to continue to rise. The requirements of care need for this population outstrip the present level of informal care provision by social and health services, care and nursing homes etc. resulting in a care needs gap. This gap is being filled by informal carers – family members, friends and neighbours who provide care to the elderly and infirm in their own homes, without formal payment.

Research into carers has been considerable – we know who carers are, how they care and how much, but the actual experience of carers remains under-researched. Consideration to how carers experience caring, how they see themselves and the change to their lives has been scant. Essentially, how carers' self-identity transitions with the onset or changes in informal care is not understood.

The objective of this research is to address this gap in the knowledge by identifying types of 'distance' associated with and affecting care identities and their relationships with others and to understand the transitional process of self-identity in carers.

Using the lens of self-identity and the construct of 'distance' this phenomenological study revealed how carers transition from their previous identity to that of carer. A total of 31 face to face interviews and statements with carers and care recipients in East Yorkshire and Hull took place throughout 2016, data was transcribed and analysed using an abductive approach. The research revealed four concepts of distance associated with and affecting carer identities and relationships; Geographical/Physical; Social; Psychological and Emotional. Of these four, emotional distance was identified as a method for carers to manipulate their self-identity between their previous identity and that of a carer.

A conceptual framework was developed that reflected the transitional process of carer identity using motivators, moderators and manifestations to highlight the transitional process and re-positioning of carer identity on a continuum between previous life, activities, roles and responsibilities (their previous life identity or

PLI) and carer life, activities, roles and responsibilities (their carer life identity or CLI).

This study assists in understanding the wants and needs of carers in an effort to improve their everyday lives and will be of interest to policy-makers, industry and charities as well as carers themselves.

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Chapter 1. Introduction

Male and female carers who look after the sick, elderly and
disabled had a suicide risk that was triple the national
average.

Financial Times (2018)

A carer is what you do, not who you are.

Lola, Carers UK Forum (2007)

The subject of caring for the elderly is becoming increasingly publicised as a major issue for current society. The changing demographics of the UK population mean the number of old, infirm and/or disabled individuals is steadily rising, whilst funding available for the provision of formal care services is essentially falling (Age UK, 2015) This has resulted in a rise in the number of informal carers – family members, friends or neighbours who provide regular care to the elderly, often ensuring that they are able to remain residing in their own home. The plight of these often unseen carers is not well understood. Their experiences of caring and the impacts on their own life are not well researched, despite acknowledgements that they are an important source of care (Carers UK, 2017), often suffer personally from the burden they carry (Schulz and Sherwood, 2008), and put the needs of their care recipient above their own etc. (Bevans and Sternberg, 2017). Therefore it is imperative that research attempts to understand the experience of informal carers in an effort to improve their everyday lives.

The inception of informal care arrangements often mean that roles, responsibilities, priorities and the very fabric of their lives change, often permanently. This results in self-identity changes; previous identities are stripped away and replaced, either by degrees or wholly, with a carer self-identity and these changes are most often unwelcomed by the carer. The transition of carer identities is not a simple process and is individual, depending on the specific circumstances of each and every carer.

The aim of the study is to understand the transitional process associated with caring identities by understanding the impact that distance has on it. In order to

achieve this, it is necessary to consider and identify types of distance affecting the informal carer identity and its relationship with others and to understand the process by which identity transitions take place in informal carers. In order to do this, Chapter 2 demonstrates the extant research which was examined to identify what is already known about carers and the carer experience. This includes the current picture with regards to elderly care – what issues exist in society around the provision of care for the elderly and why it matters; who carers are as a group – what relationships they have with the people they provide care for and how social, demographic and individual circumstances (such as residential arrangements and employment) influence them; What factors affect carers as individuals - what they are effected by and what alters the care they provide; and how caring affects identity – what constitutes the carer identity and how it is managed by carers.

The UK population is growing increasingly old and infirm and requires more care than formal care can currently provide. Public Health England (PHE) published their "Recent Trends in Life Expectancy at Older Ages" report on 12th February, 2016. This report confirmed that in the UK, death rates have steadily declined over recent decades and that in, 2014, 55% of all deaths in England occurred in people over the age of 80 years (PHE, 2016). The report also showed increased average life expectancy of those aged 65 from 13 years in 1981 to 19 years in, 2014 in males and from 17 years to 21 years in females. The UK population is currently at its largest (ONS, 2017), the population are living longer (PHE, 2016) but are suffering from greater ill health (PHE, 2016). This results in a larger number of older people requiring care. This care need has (in part) been fulfilled by Local Authority Social Services and private enterprises worth £132 billion per year (Carers UK, 2017), however, social care budgets continue to fall year on year, despite increasing demand (Age UK, 2015). Research has demonstrated that this results in a care need gap which is often filled by informal care (Bolin, Lindgren and Lundborg, 2008). Informal care is most often provided by relatives of the ageing (Checkovich and Stern, 2002; Szinovacz and Davey, 2007). In fact Henz (2006) states that approximately three quarters of British frail elderly are in receipt of informal care. Henz (2006) also revealed that approximately 16% of the British adult population identified themselves as carers according to the General Household Survey, 2002. In fact

the number of informal carers in the UK is predicted to hit 9 million by 2037 (Carers UK, 2017). However, changing demographics have resulted in the provision of informal carers actually contributing to the growing problem. Birth rates in the UK are falling, meaning there are fewer adult children to provide informal care to parents (Tolkacheva, Broese van Groenou and Van Tilburg, 2014) and increasing divorce rates have resulted in fewer spouses willing to provide care (Gans, Lowenstein, Katz and Zissimopoulos, 2013).

The majority of carers are either adult children or spouses (Government Office for Science, 2015) however, filial caring experiences are not the same for all. The division of caring labour between siblings has been shown to be affected by other aspects of the carer's life such as employment, geographical proximity, marital status and age (Checkovich and Stern, 2002; Leinonen, 2011). Care provided by spouses is on the increase (Hoff, 2015) and may be the only informal care option for couples who do not have children (Allen, Lima, Goldscheider and Roy, 2012). Spouses were shown to be better placed to provide care as they generally co-reside with the care recipient in most cases, but may also struggle to provide care over time as their own age advances and their own needs increase. Informal care can also be used as an intergenerational example of familial bonds (Vincent, Phillipson and Downs, 2006) with Grandchildren and the wider family members working together to provide care.

Informal carers are generally female (Finley, 1989; Hiedemann and Stern, 1999; Laditka and Laditka, 2000) and provide a greater amount of care if they are not married (Stoller, 1983). The gendered nature of personal care tasks, such as washing was also revealed to make female carers more socially acceptable as primary care givers (Dwyer and Coward, 1991; Stoller, 1983) although Stoller (1983) also argued that it is the culturally ascribed roles of domesticity that mean women provide more care than men. Female carers were also found to be more likely to manage multiple demands on their time, such as employment and other family responsibilities (Barnes, Given and Given, 1995) and so use leisure time to provide informal care (Del Rio-Lozano, Mar Garcia-Calvente, Marcos-Marcos, Entrena-Duran and Maroto-Navarro, 2013).

Carers are affected by a range of geographical considerations such as their proximity to the care recipient (Lawton, Silverstein and Bengtson, 1994), community setting (Gilleard and Higgs, 2005) and whether they reside in an urban or rural location (Creese, 2003) and are located close to services and amenities (ILC, 2013). Older residents in rural areas suffer from growing isolation, loss of services and high costs of living (ILC, 2013) however, research suggests that levels of rurality, wealth and caregiving arrangements are all interrelated (Phillimore and Reading, 1992). Different cultural expectations also exist in rural areas (Heenan, 2008) whereby carers accept caregiving as an extension of normal familial duties and are therefore less likely to self-identify as a carer (Heenan, 2008). Community support networks for care givers may be more common in rural regions (Dwyer and Miller, 1990), assisting with informal care provision and support in the absence of formal services.

The propensity for a carer to provide care is motivated by many factors, including love, affection, duty and obligation. A pre-requisite level of affection to inspire care exists (Engster, 2005; Leira, 1994) but moreover, research suggests the greatest motivators to provide care are senses of moral duty and familial obligation (Oudijk, Woittiez and De Boer, 2011; Daly, 2002) and the greater the perceived obligation, the greater the amount of care given and the emotionally closer the relationship (Cicirelli, 2000; Engster, 2005; Stuifbergen, Van Deldem and Dykstra, 2008; White-Means and Hong, 2001).

The effects of caring on the carer has been subject to a great deal of research in recent years and in particular, the effects of loneliness and social isolation (Jo Cox Loneliness Commission, 2017). Caregiving stress is common due to the dynamic nature of the role and the multiple demands placed on carers (Bevans and Sternberg, 2012). In fact carers are likely to suffer from increased burden and from multiple demands for longer due to increased life expectancy (Couch, Daly and Wolf, 1999). The burden of multiple roles affects the quantity and quality of care provided to care recipients (Stephens and Franks, 1999) but also affects the wellbeing of the carer and anxiety, depression and insomnia have been found to be symptoms of carer burden (Bevans and Sternberg, 2012). Carer burden has also been found to affect carers relationships with others and can result in damage to relationships among the wider family unit (Dooghe,

1992; Leinonen, 2011). Tensions emerge as new caring responsibilities are assigned, family rituals are altered, financial changes are worked through and self-identities change (Dean, Kellie and Mould, 2014; Leinonen, 2011).

Identity is made up of a number of narratives – the personal narratives of identity, value and relations (Abma, Bruijn, Kardol, Schols and Widdershoven, 2012) and the carer identity can only exist where there is a corresponding cared for identity (O'Connor, 2007). Even then, some individuals may struggle to see their caring role as anything more than societal expectations and an extension to their existing identity (O'Connor, 2007). The acceptance of the carer identity has both positive and negative consequences in that carers may become more likely to seek assistance from others once the carer identity is accepted, but this acceptance may also strip away old relational identities such as daughter or husband and alter the fabric of the relationship between the carer and cared for forever (O'Connor, 2007). The acceptance of the carer identity can also be problematic on the death of the care recipient when the identity of carer effectively ceases to exist (Broady, 2017) but can be made easier if some aspects of the previous identity remain in the new caring identity (such as a hobby or certain social circle) (Broady, 2017).

Complex informal network dynamics occur in families as one or more member's transition to the carer identity (Allen et al., 2012). These changes can result in tensions among the wider family as new roles and responsibilities develop in areas of family life not previously considered (Dean et al., 2014) which may ultimately change the way that that the family *"does family"* (Barnhart, Huff and Cotte, 2014). The development and transition of individual and family identities can be constructed through the repetition of family practices or rituals (Cheal, 2002) which confirms that identity both internally (to the family members themselves) but also to the outside world (Higgins and Hamilton, 2014). The adoption of caring identities often provides a catalyst for the renegotiation of those family rituals (Trees and Dean, 2018) which can also be a source of tension amongst family members (Dean et al., 2014). Family rituals are often emotive and may use objects and possessions to accumulate personal and emotional value (Epp and Price, 2010). The emotional value of an object can then be used as an aide memoire, to provide emotional connection to a time or

activity no longer experienced (or altered) or even as a tool to manipulate behaviour (McCracken, 1987). In fact, possessions, objects and associated rituals may have such symbolic value among individuals and families that they actually become part of the family construct (Barnhart et al., 2014). Various aspects of informal care have been studied including gender differences, sibling differences, effects of employment, marriage, ethnicity etc. However, few studies have focused on qualitative understanding of the informal care relationship – the 'why' instead of the 'what'.

This thesis focuses on interpreting the social world, to describe the experiences of carers in their everyday lives, by understanding the phenomenon of their experiences through their eyes (Creswell, 1998). Therefore a phenomenological approach has been used to emphasise the requirement to describe and understand from the perspective of the participants – *"whatever appears in the manner in which it appears"* (Moran, 2000 p.4). The research was conducted via a number of semi-structured interviews and carer statements with participants in Hull and East Yorkshire. Each participant was a self-recognised carer for a care recipient aged 65 years or over, however a small number of care recipients were also interviewed. Data collected was then transcribed verbatim and interrogated using abductive analysis strategies. More detailed descriptions of the method and methodology of this research can be found in Chapter 3.

The aim of this thesis is to understand how individuals transition from their previous identity to that of an informal carer, using the following objectives:

1. To understand the impact of distance on informal care identity and its relationship with others.
2. To understand the transitional process associated with self-identity when informal care provision commences or changes.

Chapter 4 of this thesis presents the main findings of the research. Firstly, four concepts of distance affecting carers are identified; geographical/physical, psychological, social and emotional, addressing objective 1. Each of the first three distance concepts are explored through the eyes of the participants and

the idea of an optimum distance for each is introduced, personalised to the individual circumstances of the participant. Each distance concept is related back to the self-identity of the participant to understand the impact on it, thereby formulating the basis for the achievement of objective 2. Emotional distance is identified as the main concept affecting identity transitions and its links to the three other distance concepts demonstrated. Emotional distance is then divided into aspects of the carer identity transition, including direction of transition (desire to increase and decrease emotional distance), tools for assisting transitions (how and why transitions occur) and what changes occur to self-identity.

The discussion chapter of this thesis (Chapter 5) reintroduces the reasons why this research is important. Findings from this research are compared to what is already known in the body of literature and the evidence this study adds is clearly highlighted. Objective 1 is revisited and the concepts of distance in relation to carer identities are demonstrated as an exciting and new contribution to the body of knowledge. The precis of an optimum distance is reviewed as a theoretical concept for carers attempting to manage their identity for each of the distance concepts. Objective 2 is then addressed and the theoretical transition of carer identities is identified and explained. The process by which identity transitions occur is illuminated through the use of motivators (why carers may desire their self-identity to change), moderators (tools that carers may use to aid them in transitioning their identity) and manifestations (what changes to their identity carers may make). This process is then developed into a theoretical framework which depicts the carer identity transition process. This process begins with a motivation for desiring a change to self-identity, through the manipulation of emotional distance in an effort to achieve their specific, individual optimum distance. Moderators are then used to alter the carers self-positioning on a continuum between the carers previous identity and an identity that is entrenched in the carer role. After re-positioning on this continuum, certain changes to self-identity have occurred which the carer will either be content with or not. If content, the position of the carer's identity will remain static on the continuum until further motivators occur. If not content the carer will re-enter the process again until an ideal position on the continuum is secured.

This cyclical transition process is illustrated, and a real-life worked example provided in chapter 5.

This research addresses a crucial gap in knowledge regarding carer identities – how they manifest, what motivates changes in identities and the process by which these changes occur. The validity of the research is highlighted in Chapter 6, along with potential limitations of the work. Chapter 7 confirms the contribution of the work – by considering the experience of carers through qualitative design, this research conceptualises the notion of 'distance' affecting carers and their identity and, using distance as a lens, seeks to understand the transitional process of the self-identity of carers by identifying their motivations to change identity, the tools they use to change identity and examining the resultant changes to their identity. This research makes a significant contribution to extant research on carers because understanding the motivations, processes and results of self-identity changes in carers (which this research provides) will assist in identifying unmet needs and wants of this specific population. This in turn will be useful to a number of groups, including other carers, marketers, policy makers and statutory and voluntary service providers. The research however, was limited in scope due to the regulations of time and length of the PhD process. Chapter 7 concludes with suggestions for future research, based on the findings and theories identified through this work.

Chapter 2. Literature Review

This chapter serves to critically evaluate the extant literature to understand the significance of informal caring, carers as a group and as individuals and how decisions are enacted in informal care relationships. The chapter begins by considering population demographics and changes in the way people live which has led to the vexed issue of social care provision for the elderly. Next, the review introduces carers as a group and identifies who they are and how they live. Narrowing the focus further, the review evaluates our current knowledge about these carers as individuals including how caring has an impact on their lives. The review then conceptualises the notion of self and identity and considers how the self-identities of those involved are affected by caring. The review also focusses on how informal carers utilise tools such as rituals and practices, objects and possessions to support or erode carer identities. The review clearly identifies a gap in the knowledge of informal caring – that carer identities and their transitions are currently not well understood. This is a requirement for policy makers and marketers if the wants and needs of this group are to be addressed.

2.1. Elderly Care – What's the big deal?

The structure of modern families and the changing roles within have been subject to a great number of studies in recent years as experts try to understand the changing demographics experienced in the UK. Dean et al. (2014) suggested that within modern family life, family roles have changed significantly, primarily because of increases in life expectancy. This shift in population demographics has resulted in a greater proportion of UK residents aged over 65. Unfortunately this ageing population also leads to an increased prevalence of chronic diseases requiring treatment. These two factors result in significantly increased caring needs for the existing UK population – a need that is currently struggling to be met (Arber and Ginn, 1990; Cracknell, 2010; Szinovacz and Davy, 2007; Waltz and Mitchell, 2007). Perceptions regarding level of care required and the length of time care may be needed for are also often underestimated (Walz and Mitchell, 2007). This section considers elderly care and its provision by firstly considering definitions of 'elderly' and 'caring' and

then describes the changes in contemporary culture which has brought about the increased need for informal caring.

2.1.1. What is 'elderly'? – Definitions and interpretations

To understand the caring problem affecting the UK elderly population, it is of vital importance to understand the exact nature of this population, firstly by determining what is meant by 'elderly' and which UK residents can be categorised as such.

The Oxford English Dictionary Online (accessed 25/10/15) defines old age as *"The later part of life; the period of life after youth and middle age; the state of having existed for a long time, usually with reference to deterioration"*. This definition provides an interpretation of life divided into three equal parts but does not specify age ranges unlike other definitions. According to the World Health Organisation (WHO, 2002) the United Nations has agreed that 60+ years old may be denoted as old age, however, it is accepted as 65+ years in most developed countries due to statutory retirement ages which are exclusively based on the passage of time in an individual's life.

Although age is an empirical measurement of time since birth, ageing can be interpreted in many ways through individual experiences, both biologically and socially. Heslop and Gorman, (2002) suggests that the use of employment retirement age as a general consensus for the UK population is acceptable, but that this cannot be applied to other countries. Developing countries define ageing through loss of sociological roles which may or may not be accompanied and/or associated with physical ailment/decline (Heslop and Gorman, 2002; WHO, 2002). In this interpretation, becoming elderly takes into account a change in self-identity – from the previous identity with its social contribution, to a new identity with a reduction in social involvement.

> In developing countries old age…is seen to begin at the point when active [social] contribution is no longer possible.
>
> Heslop and Gorman, (2002 p.4)

The family life cycle uses a developmental approach to consider family from a disciplinary perspective. The refinement era includes ageing family members

from retirement to death and so the older, or third age stage begins at retirement (Murphy and Staples, 1979). However, this is challenged by Gilleard and Higgs, (2005) who comment that ageing and definitions of elderly are changing – changes in the life-course and the development of the third stage of consumption demonstrate that individuals are living longer and the age of retirement no longer defines an individual's entry into old age – that they remain productive (Gilleard and Higgs, 2005). Vincent et al., (2006) agree that the productivity of the older generation needs to be considered outside of their contribution as workforce – that elderly individuals remain productive – they provide *"social meaning and personal satisfaction" (Vincent et al., 2006 p.116)* and consider the existence of a fourth age, a transition whereby productivity eventually ceases.

The definition of elderly is a changing, geographically explicit, socially constructed concept; therefore becoming elderly denotes much more than the simple passage of time, and includes an individual's ability to perform everyday consumption activities (Barnhart and Penaloza, 2013). The current UK retirement age is used for state pension eligibility in the UK and therefore services for the elderly also become available at 65 years (for example the attainment of a bus pass, winter fuel payments etc.) Although social changes affect the attainment of old age, for the purposes of this research, the population considered elderly are 65 years old and over, in line with WHO (2002).

2.1.2. What is 'caring'? – Definitions and interpretations

The concept of caring is complex and problematic and it is becoming increasingly important to understand how caring is conceptualised and characterised in practice. Extant literature demonstrates that issues in the provision of care is not new, in fact seminal work regarding carer and care definitions and experiences were produced by Stoller in the 1980's. Leira and Saraceno, (2002) confirm that until the 1970's the concept of 'care' was relatively straightforward, but more recently scholars have acknowledged that the examination of the care concept is complex and enduring (Leira and Saraceno, 2002). Because of this, research conducted in the 1970's remains

relevant to current research as, despite the longevity of research on the topic, caring remains a problematic subject in which researchers have yet to reach concurrence.

Because 'caring' means different things to different people, individual research on any caring topic should therefore include an internal definition of what the terms mean within that research context, however this is also geographically varied (Leira, 1994), changing with time (Arber and Ginn, 1990; Thomas, 1993) and relies on the acceptance of caring as an activity outside of the usual roles and responsibilities of the studied relationship (Arber and Ginn, 1990); that the self-identity of the carer does not already include the provision of care.

> [Caring is] activity without a name, activity traditionally assigned to women, often carried out in family groups: activity that I know from experience but cannot easily label.

> DeVault, (1991 p.4)

In an article for the Institute of Social Research, Oslo, Leira, (1994) suggested that the conceptual challenge of understanding the labels of 'caring' 'care' and 'carer' have prevailed since the late 1970's. Leira, (1994) suggests that the provision and distribution of responsibilities in caring for elderly family members is under-researched and its' importance under-theorised. This opinion is shared by Arber and Ginn's study in 1990 in which they confirm caring is *"vague and undefined, encompassing a wide range of activities and relationships"* (Arber and Ginn, 1990 p.429). Engster, (2005 p.50) supports this viewpoint, describing the term 'caring' as an *"underdeveloped…basis for a moral and political philosophy"* and questions the lack of an agreed definition of *"our moral obligation to care"*.

Arber and Ginn, (1990) suggest that this interpretation can vary, depending very much on individual perception:

> Ten years ago the terms 'caring' did not exist – it did not merit an entry in dictionaries. Not only is the term now common in usage, but it is emotive and value-laden: carers are perceived as good, although undervalued, performing arduous tasks for little, if any, reward and saving the state a great deal of money

> Arber and Ginn, (1990 p.430).

A common interpretation of 'caregiving work' is to provide care to those who are unable to provide care for themselves. Waerness, (1982) cited in Leira, (1994 p.188) defines 'caregiving work' as:

> The caring for those members of society who, according to commonly accepted societal norms, are not able to care for themselves and in which case an equal, reciprocal give-and-take relationship of providing and receiving care cannot be established when it comes to help and support in everyday life.
>
> Waerness, (1982) in Leira, (1994 p.188)

Leira, (1994 p.188) agrees in that *"persons who are not able to care for themselves represent a stronger moral claim on others to intervene than do perfectly fit persons"*, suggesting that care need is dictated by physical (in)ability and care provision dictated by moral rectitude.

Thomas, (1993) agrees that the concept of care is not uniformly defined and changes over time. Thomas' study involved deconstructing and comparing concepts of care from the 1980's before attempting to formulate a unified concept of care (Thomas, 1993) and found that:

> Definitions of care are constructed such that boundaries are differentially drawn around what constitutes care, with the effect of excluding or including sets of social relations in definitions of caring relationships.
>
> Thomas, (1993 p.649)

Thomas, (1993 p.667) argued that *"a unified concept of care could provide a useful starting point in care research"* and argued that the definition of caring is problematic; relying on interpretation by those involved and that essentially, care means different things to different researchers (Thomas, 1993). Caregiving may involve connotations of affection and moral obligations and varies according to a number of considerations, as demonstrated by Thomas' (1993) unified concept of care. However, research has to date failed to consider how motivations to provide care (such as moral obligation) affect the care relationships and the self-identities of those involved. The Kings Fund, (2006) agreed that the term 'informal care' can be misconstrued:

> 'Informal care' is a misleading term for the magnitude of the task it describes and the dedication of the individuals who

perform it. There is debate over the correct term to use for carers who provide support in these circumstances

Kings Fund, (2006 p.138)

However, in all research accessed to date, 'caring for' has always included aspects of assistance with everyday life, including personal care tasks such as bathing and dressing, or ancillary tasks such as shopping or even DIY, especially where the care recipient suffers from multi-morbidities (Schmidt, Ilinca, Schulman, Rodrigues, Principi, Barbabella, Sowa, Golinowska, Deeg, and Galenkamp, 2016). The inception of informal care causes the carer to take on a greater responsibility for tasks previously not undertaken, to become 'the carer' for their care recipient, essentially transitioning their identity from its previous role, responsibilities and activities to a new, unknown identity. Therefore, for the purposes of this research, caring is defined as providing some level of assistance or support with everyday living for an elderly individual.

So far in this section, the definitions of elderly and caring have been discussed and confirmed. The next section considers the reasons why informal caring is such an important topic requiring further research.

2.1.3. Population demographics - Life expectancy and chronic morbidity

The UK population is currently at its largest ever (Office for National Statistics, 2017). Not only does this contribute to issues around scarcity of resources, but changes in population demographics have seen an increased life expectancy in the UK (Age UK, 2015; Gilleard and Higgs, 2000; Office for National Statistics, 2017). Public Health England (PHE) published their *Recent Trends in Life Expectancy at Older Ages* report on 12th February, 2016. This report confirmed that in the UK, death rates have steadily declined over recent decades. The report also showed increased average life expectancy - essentially, UK residents are living longer and increasing population size.

Cracknell, (2010) stated that 10 million people in the UK are over 65 years old and that projections predict this figure will increase to 19 million by 2050. However, healthy life expectancy is not predicted to increase as fast, resulting in proportionally greater demands on public services (Gray, 2005). Age UK, (2015) supported this finding, suggesting that disability-free life expectancy is

not keeping pace with overall life expectancy. Brayne, Matthews, McGee and Jagger, part of the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS), (2001) declared that:

> Ageing of the population is associated with marked increases in morbidity. Few individuals over the age of 64 report no physical disorder.
>
> Brayne et al., (2001 p.60)

This view is shared by a number of other researchers, including Mendelson and Schwartz, (1993) who described the "baby boom" generation as hitting 65 years old between now and 2030, resulting in a larger proportion of the UK being elderly and in less robust health. Age UK, (2015) confirmed that most people over the age of 75 have one or more health conditions (because chronic disease is more prevalent in older age groups – Age UK, 2015) and that 1 in 10 UK residents over 65 are classified as frail, increasing to 1 in 4 over 85 (Age UK, 2015). Essentially, the UK population is not just ageing, but many of our more elderly population are increasingly suffering multiple morbidities, disability, increased frailty, and are at risk of further health problems which require support in the form of care. Thus, the increasingly elderly population of the UK with increased levels of morbidity has serious consequences in terms of increasing the need for care.

This section has considered the UK population and has highlighted issues relating to the number of elderly and infirm individuals in the UK. The next section considers caring needs and the implications for the provision of care for this section of the population.

2.1.4. Funding of care and social trends

Formal care in the UK is supplied by a range of social services, including local Government and through private care companies. This care is worth an estimated £132 billion per year to the UK budget – a figure which is similar to the entire NHS annual budget (Carers UK, 2017). Age UK, (2015) confirmed that there has been a £1.95 billion reduction in the UK Government social care budget over the last ten years which is likely to continue to reduce year on year, effectively providing less and less funding for a greater number of people in

need. Not only have overall social care budgets been cut (Age UK, 2015), but Government spending on home care specifically reduced by one fifth between, 2010/11 and, 2013/14 with 15% fewer older people receiving some provision of formal care (Age UK, 2015). The provision of formal care is dependent on the finance of the individual considered and individual assessments are completed to allocate care provision in hours depending on the level of care need (East Riding of Yorkshire Council, 2018). Because of the limitations of formal care provision (unmet need, inability to afford care provision etc.) a large proportion of individuals rely on informal care either as an exclusive care source, or as an addition to formal care. (Bolin et al., 2008; Kings Fund, 2006). This informal care is largely provided by family members, who have limited financial support, and is failing to keep pace with the number of elderly infirm individuals which require some form of care (Kings Fund, 2006).

Walz and Mitchell, (2007) and Szinovacz and Davey, (2007) confirm the existence of increasing need for informal carers, but suggest that the number of potential caregivers for each person in need of care is decreasing, adding to the issues with care provision, and agree that there are rising concerns regarding the care of the elderly due to the increase in numbers requiring care and the shortfall of caregivers.

One reason posited for the low number of available informal caregivers is that population demographics have demonstrated falling birth rates in the UK (ONS, 2016). This is supported by Horowitz, (1985) and Tolkacheva et al., (2014) who raise concerns for filial caring patterns in the future as the number of offspring a couple has continues to fall and hence, there are fewer offspring to take up the identity of carer for elderly parents as they become adult themselves.

> Because of an increased average life expectancy and a decrease in birth rates, informal care must be delivered to the elderly for a longer period of time and by fewer children, increasing the pressure on an individual child
>
> Tolkacheva et al., (2014 p.313)

A further problem is that increasing rates of divorce result in fewer spouses to provide informal care, hence the care burden falls increasingly on the shoulders of adult children (Gans et al., 2013). Lin, (2008) also examined the association between parental divorce and informal care provided by biological offspring.

Roberts, Richards and Bengston, (1991) as cited by Lin, (2008 p.114) suggest that *"divorce weakens the bonds between generations"* and that this effect increases with time, suggesting therefore, that adult children are less likely to adopt the carer identity for parents who divorced when the child or children were young. Lin, (2008) admits however, that there could be key differences in the familial characteristics which make up a family containing divorced parents compared to those of a family without divorce and that these key differences may also relate to the propensy of the adult children to provide care in later life (for example, the presence of domestic violence etc.) However, research into the propensy of adult children and spouses to provide care has not considered how the absence of offspring and/or divorce affects family identities, or how they may alter at the inception of caring.

Firstly, this section considered alternatives for the definitions for 'elderly' and 'caring' in an attempt to anchor this research within existing and accepted research terms. Secondly, the population demographics of the UK were considered which highlighted increases in life expectancy and morbidity. These two aspects confirmed that in the UK, there are a great number of elderly individuals that require care. The section then considered the provision of formal and informal care and found that the provision of formal care was not keeping pace with the demand for care – a gap between need and resource existed. Informal care provided primarily by family members was identified as being of great importance in providing care and filling this gap, however is struggling to keep pace with demand, due to demographical changes such as decreased birth rates and increased divorce rates. The next section will examine informal carers, who they are and how they provide care and seek to understand the different types of care that is given.

2.2. Who are carers?

Research studies, population statistics and individual accounts confirm that the need for care is increasing (Age UK, 2015). Patterns of life expectancy and costs of long term care provision will result in a re-emphasis of care providers from residential settings to care in the community - the family being the "*first line of defence' in providing community-based care*" (Allen et al., 2012 p.362)

This section considers the question, who are informal carers? Provision of informal care is primarily through unpaid family members who may co-reside or not, with the care recipient. This section considers care provided by adult children, spouses and other family members and also highlights differences in the informal care provided according to gender, employment and social/demographical differences. It is important to understand who carers are – the marketplace is currently constructed for 'normal families' (Mason and Pavia, 2010), therefore carers are a group where better understanding is required to comprehend their consumer behaviour (Mason and Pavia, 2010).

2.2.1. Filial care

Significant research into family caring (Checkovich and Stern, 2002; Leinonen, 2011; Tolkacheva et al., 2014) has focused on siblings – the division of caring responsibilities between siblings and the effects on the relationships of those involved. Leinonen, (2011) focused on care participation patterns amongst adult siblings caring for elderly parents and concluded that sibling care involvement can be divided into 3 distinct groupings; togetherness – whereby siblings work as an effective caring team; backup – whereby one sibling is in a primary caring role whilst the other takes responsibility for certain tasks or at certain times etc.; and absent – whereby one or more siblings provides no care at all. Interestingly, the findings showed that the majority of respondents saw themselves as the primary caregiver and the majority did not wish to alter the care proportionality between themselves and their siblings; the primary caregiver had fully adopted the carer identity with no desire to share it. A further interesting distinction made in the study was that employment status and working hours were key determinants in the division of care responsibilities in filial care relationships. This suggests that siblings may limit their adoption of a

carer identity and maintain their previous identity with specific emphasis on their employment and how it relates to the way in which they see themselves.

Checkovich and Stern, (2002) suggested that previous research had been focused on the role of a single child as the primary caregiver and had not paid enough attention to shared care arrangements between siblings. However, the study concluded that the majority of care is indeed provided by a single primary caregiver. The study found that factors such as the carer's gender, geographical distance from the parent, work status and number of siblings affected the carer's decision to care and likewise, factors such as parent's age, gender, marital status and level of disability were statistically significant in determining caring decisions. This was challenged however, by Tolkacheva et al., (2014) who found that in the majority of the families they studied, care was provided by two or more siblings. This research did not consider however, how the sharing (or not) of care responsibilities affected familial identities and the self-identity of the carer themselves.

A further consideration in filial caregiving was identified as employment patterns. The decision to provide care rather than seeking formal care provision and the ability for an adult child to actually provide care was linked to their employment status (Checkovich and Stern, 2002) - those who work less tend to care more (Checkovich and Stern, 2002; Seay, 2010; Tolkacheva et al., 2014) because they have additional hours of free time to provide that care, and are more likely to immerse themselves within the carer identity.

This was supported by Leinonen, (2011) who agreed that the division of care labour among siblings was dependent on employment status and conditions:

> The assumption in this study is that employment status and working hours are major factors in adult children's views about the equitable division of care responsibilities.
>
> Leinonen, (2011 p.309)

Differences in gainful employment definitions were not considered however and so number of hours in paid work were not compared or linked to caring output, for example, part time and full time work differences, shift patterns and type of employment between filial carers could potentially affect the provision of care to elderly parents. The research suggests that the sibling with the least

employment would take the majority of the caring burden (Leinonen, 2011), however employment and carers will be discussed in more depth later in this chapter.

A further pertinent point raised by Leinonen, (2011) was that care relationships between siblings may be unequal due to geographical proximity – that it is in fact the sibling who resides closest to the elderly parent who provides most care, irrespective of employment status. This was supported by Checkovich and Stern, (2002) who also found geographical proximity to be a significant factor, however also identified other factors such as marital status, age and level of infirmity as significant. Geographical proximity and its effects on caring are also discussed in greater detail in the next section.

2.2.2. Spousal care

As well as adult children providing care, spouses often perform caring tasks for their husband or wife and are in fact, the fastest growing group of informal care providers (Hoff, 2015). Differences between spousal carers and adult child carers include geographical proximity (spouses routinely co-reside with their care recipient), employment status (spouses are generally of similar age as their partner and so do not go out to work) and responsibilities for other family members (spouses' children will be adult if the care recipients children are). Spouses are also sometimes the only family member available to perform care if the couple have no offspring. The identity of carer is more easily and readily adopted by spouses because of the proximity (both physically and emotionally) to their care recipient. Allen et al., (2012) claimed that spouses are more suitably placed for the role of carer but become unable to perform the specific tasks required over time. Increased infirmity and age of both the spousal carer and their care recipient over time require further input of informal or even formal care. In fact, Hubert and Hollins, (2000) suggest that households with elderly carers providing care for elderly care recipients may have a number of individual and joint needs which may conflict. Informal care provided by spouses is projected to increase in coming years due to improvements in life expectancy of males (and hence more elderly males alive to provide care to their wives) (Pickard, Wittenberg, Comas-Herrera, King and Malley, 2007). In

fact, Brunner and Ahmadi-Abhari, (2018) suggested that the dependency of elderly men (and therefore care needs) will diminish and women's will expand due to changes in the relative health of the sexes, with women predicted to suffer a greater number of years in declining health in the future. Spousal carers face *"unique challenges as they adapt to the demands of caring whilst experiencing significant losses in their couple relationship"* O'Shaughnessy, Lee and Lintern, (2010 p.237). In essence, spousal carers struggle to meet their own needs and those of their care recipient and worry about the future and their ability to cope with the emotional and practical issues associated with caring (O'Shaughnessy et al., 2010).

2.2.3. Other family members

Although the majority of informal caring is provided by spouses and adult children, other family members can also be involved in caring for elderly family members.

Because of increasing lifespans in Europe, families are experiencing *"longer years of shared life across generations"* (Bengtson and Lowenstein, 2003 p.11). It is suggested (Hank and Buber, 2009) that this may result in the increasing importance of multigenerational family bonds, especially in familial caring, which can lead to Grandchildren assisting or providing care for elderly family members. Rather than one family member adopting the full carer identity, aspects may be shared around many members. Thus, many family members' self-identities change in a number of small ways, rather than one member's identity changing significantly. This also means that changes in care need can be responded to, with greater or fewer members taking on aspects of a carer identity as the needs of the care recipient change. Vincent et al., (2006) confirm the importance of intergenerational kinship ties. The provision of close intrafamilial bonds has gained importance and focus due to increased lifespans allowing individuals to occupy kinship roles for longer (Vincent et al., 2006). This in turn lengthens the duration of life stages within the life-course and lends itself to increased intergenerational support, solidarity and transfers (Vincent et al., 2006), and occupying a limited carer identity for longer.

A further issue in multigenerational informal caring is the potential overlap of family members requiring care. Traditionally, care focused on the younger generation until such a time as the need for this care was obsolete; the care providers then being free to consider and focus care giving resources on the older generation. The result of delayed reproductive patterns and increased life expectancy has resulted in a potential overlap between the two groups (Gans et al., 2013). It has also been suggested (Skolnick and Skolnick, 2003) that there has been a lengthening on the adolescent period in recent times, although the level of care required by adolescents is unclear – in fact it is conceivable that these adolescents could actually contribute to the care giving team, either directly by providing certain caring tasks to the elderly family member, ultimately sharing the carer identity with the wider family, or indirectly by contributing to the overall household workforce, freeing up more resource for adult carers to invest in the elderly care recipient (Hoff, 2015). This theory of overlapping care demands is supported by Hank and Buber, (2009), and actively involves *"intergenerational solidarity"* (Silverstein, Conroy, Wang, Giarrusso, Bengtson, 2002 p.S6). However, the prevalence of co-residence in the intergenerational solidarity model (Silverstein et al., 2002) has led to confusion and misunderstanding regarding the definition of caregiving. Hank and Buber, (2009) suggests that low level caring by multi-generations is not recognised as such, leading to the conclusion that caring was only recognised once it exceeded a certain intensity (Hank and Buber, 2009). This supports Thomas, (1993) in confirming the need for a carer identity to be recognised as such, which can only be done by the recognition of care extending beyond the realms of accepted family practices.

A method for balancing a household's caring resources between competing care recipients may be required (Gans et al., 2013) and this balance depends on the individualistic nature of the familial set up - Gans et al., (2013) state, for instance, that individuals with bigger families and younger children are less likely to care for their elderly family members. This suggests that the identity of carer could not be fully adopted as the identity competed with other familial identities such as Wife, or Mother etc. This is supported by the findings of Stoller, (1983) who also found that it was the number of children in the household, (but regardless of the age of those children) which affected the

number of hours of care provided to elderly parents. This is challenged by Campbell and Martin-Matthews, (2003) who queried the existence of research bias in terms of dependent's age. As age is an adequate predictor for care need, it follows that adult children with older children themselves will have more elderly parents requiring a greater level of care (Campbell and Martin-Matthews, 2003). Therefore it may be the need of the elderly parent which dictates the level of care provided, irrespective of the number or age of the dependent children.

One key element that Gans et al., (2013) reiterated however, was that there is a potential need for policy makers to view informal caring as a holistic entity – caring for children and the elderly alike is labour intensive and additional resource may be required for one, to allow the adult children to provide care for the other.

Comparatively little research has been completed on informal care structures which involve family members other than spouses or adult children and their spouses. Allen et al., (2012) suggests that this is because relatives other than spouses and adult children are unlikely to provide routine and continued care. Allen et al., (2012) however do suggest that in most cases a primary caregiver is supported by a secondary care giver who provides assistance, but only when asked and that this secondary caregiver is often another member of the family. This 'turn-taking' in the caring role is essential to prevent burn-out in the primary caregiver, provides opportunities to escape the carer identity (albeit briefly) and does not apply when the secondary caregiver is paid (Allen et al., 2012).

The provision of care by family members also involves the commencement of decision-making processes which involve more individuals than the care recipient alone. This new relationship between the care recipient and family carer is often made more complex when additional family members become involved in the decision making process (Dean et al., 2014). This complexity is often exaggerated by the loss of autonomous decision-making by the cared-for and the expectation of the family carer to be involved in or make decisions for that individual. This essentially incorporates a loss of agency for the care recipient and the addition of agency for the carer, changing aspects of previous

identity which can be construed as both positive and negative by those involved.

> The aging process can produce tensions not only for the person who is aging but also for that person's family, and ultimately for the intergenerational relationship

> Johnson and Spence, (1982 p.116)

In fact, Clements, (2013) argues that the inception of caring results in the loss of 'voice' of the care recipient, particularly when some form of disability is also involved. The agency of the care recipient is reduced and awarded instead to the carer (Clements, 2013).

The importance of these decisions, the method for reaching them and the tensions which may emerge because of them may have effects on the wider familial unit, affecting other members and not just those directly involved in informal care provision. However, the consideration of agency and decision-making is complex, well-researched and beyond the bounds of this research study.

2.2.4. Gender

It is well documented that care for family members is primarily provided by females in the family (Campbell and Martin-Matthews, 2003; Collay, 2002; Dwyer and Coward, 1991; Finley, 1989; Hiedemann and Stern, 1999; Horowitz, 1989; Laditka and Laditka, 2000; Raschick and Ingersoll-Dayton, 2004; Seay, 2010; Stoller, 1983)

> Reports from numerous nations indicate that in addition to children…women are the care-takers of parents and in-laws

> Seay, (2010 p.564)

More units of care are provided by female adult children and it is these women that "*still carry the larger burden of immediate and extended family responsibility*" (Collay, 2002 p.92). In effect, women carers provide more care than men and also carry a greater domestic burden (Willyard, Miller, Shoemaker and Addison, 2008). The gendered nature of caring has been subject to much research to discover why this should be the case and Finley, (1989) tested four common hypotheses for these differences: 1) time available,

2) external resources available. 3) socialisation/ideology and 4) specialisation of tasks. The results of this research demonstrated inconsistent and contradictory results and no evidence to support any of them (Finley, 1989).

> Regardless of the time available, the attitudes of obligation or the external resources available, women provide more care…in addition, males are not more likely to specialise in care management than females…The gender difference remains.
>
> Finley, (1989 p.84)

Previous research has also expounded males as feeling a lack of obligation to provide care, due to differences in gender roles (Finley, 1989). According to Finley, (1989) distinction should be made between feelings of care responsibility and acts of care providing:

> Males are as likely to feel obligated to care for elderly parents as are females, but they do not necessarily act consistently with that attitude
>
> Finley, (1989 p.79)

Society ascribes value to familial contributions which denote female family members as the natural carer (Finley, 1989). This automatic assimilation of the carer identity to the female family member needs to change if care provision is to be equitable between the sexes as *"very little behavioural change will occur in caregiving by sons until societal evaluations of men's contributions change"* (Finley, 1989 p.85).

Finley's (1989) theory of female dominance in caring is supported by Horowitz's (1985) research in which three similar explanations for female care dominance were investigated – the traditional caring roles of women, the stronger emotional ties with other family members and their increased flexible free time. The research found limited evidence to support these theories but concluded that women tend to live closer to their parents than sons, parents are more likely to move into the familial home of a daughter, rather than a son, sons only become primary caregivers for parents when there is no female alternative but also that sons are likely to have similar levels of contact with parents to daughters and that there is no evidence to support the theory that daughters are more likely to care for their Mothers and sons for their Fathers. Research

suggests that females are more inclined to take up the carer self-identity, whether that identity is caring for a male or female care recipient.

A possible explanation for the gendered nature of informal care is that female family members act as gatekeepers to the care recipient. Doheny, Kouneski and Erikson, (1998), cited by Bracke, Christiaens and Wauterick, (2008) claim that gender differences in caring are due to 'gatekeeping' by female family members and suggest that women direct the level of care and specify the care tasks provided by men and may actively discourage care involvement from men to maintain control within the family. The caring role is fully integrated into their self-identity and so sharing caring tasks must be on their terms, as to lose control of caring may be to lose possession of a part of their identity.

> Women are also known as the "gatekeeper" which means that women are ambivalent vis-a-vis the active involvement of men with important others… because it threatens their sense of control over central life domains
>
> Doheny et al. in Bracke et al., (1998 p.1352)

This research suggests that it is not male reluctance to participate in caring which has resulted in fewer male carers, but rather the discouragement of female family members. However, Calasanti, (2003) also argues that although female caregivers are notably more common in general informal caring, spousal caring is performed by as many men as women.

The gendered nature of caring tasks was also suggested as a possible explanation for increased female participation in caring. Daughters acting as carers are more likely to provide care to either parent than sons (Campbell and Martin-Matthews, 2003) but the reasons behind this may have links to previous relationship strength and familial bonds being stronger in daughters and because of the intimate nature of some caring tasks (discussed more fully in the next section). Adding to this argument, Allen et al., (2012) suggest that male carers are more likely to outsource care tasks, essentially resulting in a greater number of care transitions experienced by the care recipient when male carers are involved. Male carers may not associate their caring obligations with their self-identity – it is not 'who they are', but 'something they do'.

Hiedemann and Stern, (1999) confirmed that not only do daughters provide more care, but the care they provide is more highly valued than that provided by a son. This may well be related to the differences in caring tasks they perform, as suggested by Stoller, (1983) and Dwyer and Coward, (1991). Mothers are more likely to be cared for than Fathers, suggesting that it is not only the gender of the carer that affects caring, but also the gender of the care recipient (Hiedemann and Stern, 1999) which supports the findings by Finley, (1989).

As previously stated, Horowitz, (1985), Campbell and Martin-Matthews, (2003) and Dwyer and Coward, (1991) all found that substantially more daughters provide care to elderly parents than sons, however Laditka and Laditka, (2000) confirmed that daughters were more likely to provide personal care tasks such as bathing, dressing, cleaning and cooking, whereas sons were more likely to complete "hands-off" tasks such as financial management, shopping, transportation and DIY tasks, in effect, mirroring the *"Activities of Daily Living"* and *"Instrumental Activities of Daily Living"* considered by Stoller, (1983) and Dwyer and Coward, (1991). The findings supported Stoller, (1983) and confirmed that there were differences between son and daughter carers within their ascribed task categories, particularly in traditionally female tasks such as cleaning and food preparation. Stoller, (1983) made the point that a daughter's greater involvement with domestic and personal caring tasks was related to functional impairment of the elderly parent and could be construed as an extension of the "*cultural assignment of domestic production to women"* (Stoller, 1983 p.852), thus the carer identity is more readily accepted by females as a number of carer aspects have already been assigned to the female prior to the commencement of caring (but not noted as such until the care demand reaches a certain level). Campbell and Martin-Matthews, (2003) however, described gender boundaries, particularly for intimate care tasks (such as personal washing etc.) whereby to functionally provide this care could be construed as taboo. This theory was also supported by Arber and Ginn, (1990) and Allen et al., (2012) who also found gendered asymmetries of intimacy. Matthews, (1995) confirmed that there are actually cultural assumptions as to what constitutes gender-appropriate caring tasks and that these would naturally differ across the world.

Research suggests that it is the female caregiver who experiences more negative consequences of caring such as feelings of depression, conflict and anxiety and stress (Allen et al., 2012; Horowitz, 1985; Neal, Ingersoll-Dayton and Starrels, 1997; Raschick and Ingersoll-Dayton, 2004; Walker, Pratt and Eddy, 1995; Yee and Schulz, 2000). Barusch and Spaid, (1989) found that spousal caregivers would turn to adult children of the same gender for assistance in the first instance, and that female caregivers experienced greater burden, because generally they are younger than their male counterparts and that level of burden experienced is directly linked to the age of the carer (Barusch and Spaid, 1989). Del Rio-Lozano et al., (2013) also considered the age of the female carer and found that older females were more accepting of the carer role but that younger females were actually angry at the enforced burden of the carer role, forcibly rejecting the adoption of the carer identity and seeing caring tasks as yet another thing to do.

Del Rio-Lozano et al., (2013) found that male caregivers suffered from less carer burden than their female counterparts because they sought formal support prior to their own health and wellbeing being affected. This theory was linked to social and cultural expectations of female carers and the view that caring was an extension to expected norms within the female familial role which wasn't true for male carers (Del Rio-Lozano et al., 2013). Females felt the carer burden should be carried as a societal expectation whereas male carers felt authorised to ask for external assistance (Del Rio-Lozano et al., 2013). This theory was extended to hypothesise that male carers felt a greater sense of 'martyrdom' in caring because they consider themselves to be acting outside of normal gender roles and are therefore exceptional (Del Rio-Lozano et al., 2013). Likewise, if a female carer chose not to undertake the caring role, or even asked for assistance, she would be considered a bad family member by wider society which provided more impetus to provide care, whatever the personal cost to the female (Del Rio-Lozano et al., 2013). The research also suggested that women carers who felt that caring was a burden hid their negative feelings of the caring role from wider society due to a perceived feeling of weakness. Women were also more likely to give up leisure activities to provide care, effectively absorbing the carer identity completely, whereas men actively took time off from caring to pursue leisure activities, confirming inequalities in carer expectation between

the genders (Del Rio-Lozano et al., 2013) and a contrast between those that fully adopt the carer identity and those that adopt caring tasks as merely an addition to their current identity. In fact, O'Shaughnessy et al., (2010) confirm that gender differences in caring are more than just who does what and how much, and include differences in the perception of identity changes through relationships:

> Gender differences in spouse carers' experiences were found; wives devote more time to maintaining the relationship as their sense of self is understood in relation to the 'other', whilst men are less likely to interpret the loss of a relationship as an attack on their personal competency.
>
> O'Shaughnessy et al., (2010 p.239)

In essence, self-identity positions in care relationships are continually renegotiated and re-positioned *"in relation to one's partner and the couple relationship"* (O'Shaughnessy et al., 2010 p.251).

2.2.5. Residential arrangements

A further consideration regarding the identity of carers is their residential arrangements. Arber and Ginn, (1990) studied the amount of time carers spent caring and found it was dependent on whether the carer resided with the care recipient and the nature of the relationship between carer and care recipient – spouse, child, parent, in-law etc. and that female carers spend more time caring than males (supported by other research -, Campbell and Martin-Matthews, 2003; Dwyer and Coward, 1991; Horowitz, 1985; Laditka and Laditka, 2000).

Arber and Ginn's (1990) study also found that more time was spent caring for a care recipient residing in the same household as the carer, for example, elderly Mothers being cared for in the home of their daughter and her family, and that there was more likely to be external assistance with care (mainly via formal care arrangements) if the care recipient did not reside in the same household as the carer (Arber and Ginn, 1990). Essentially, the self-identity of carer is absorbed to a larger extent by carers who reside with their care recipient, however this may not be the optimal situation for those involved. Although co-residence was once common practice (Pezzin and Schone, 1997) the decision to move an

elderly relative into the family home for caring purposes must be extensively investigated and considered (Bursack, 2018).

Tensions in co-residence can also occur when deprivation of authority for the elder exists, a lack of role and therefore lack of clear identity for the care recipient (Gibson, 1992). Reciprocity in caring arrangements is often a motivator for the development of co-residential caring arrangements of elderly family members (Grandparents caring for Grandchildren and adult children caring for the Grandparents) (Gibson, 1992). However, this reciprocal arrangement is dynamic and ultimately terminates on the maturity of the Grandchildren. The elderly Grandparent is then bereft of former identity and role within the family and the motivator for the adult child for providing them with care can change from love and reciprocity to duty and obligation and ultimately result in the perception that the elderly relative has become a nuisance (Gibson, 1992).

2.2.6. Employment

As previously discussed in brief, employment status affects both male and female carers in their ability to provide care in terms of their free time and the financial implications of becoming a carer. One consideration for both filial and spousal carers is their own retirement plans. Selvin, (2006) argued that because of increasing life expectancy, adult children are continuing to work for longer to provide financially for elderly parents requiring care (Selvin, 2006). Not only are carers remaining in work longer, the pool of available carers is decreasing due to changes in family structure and the necessity for dual earners in families – potential carers are having to return to the labour market (Gans et al., 2013). Most carers are middle-aged females (Arber and Ginn, 1990; Gans et al., 2013; Moroney, 1976) which is the demographic that has been required to join the labour market in more recent times (Gans et al., 2013). This has resulted in an increasing gap between the number of elderly individuals requiring care and the number of these middle-aged females to care for them (Arber and Ginn, 1990; Horowitz, 1985; Moroney, 1976).

A great number of adult children caregivers will also be employed, conducting their caring roles alongside, not instead of, paid employment. The effect that this has on both the carer and the care recipient has been considered but so far

research has failed to reach concurrence. Barnes et al., (1995) investigated the effect of employment on caring and found that

> Employment does not reduce the number of hours of assistance to the dependent parent, even though the jobs often provide neither the flexibility nor the income to moderate the effects of additional demands.

Barnes et al., (1995 p.375)

If the same number of hours of caring are provided even with paid employment, the hours for caring must therefore result from the utilisation of the carers' leisure time (Barnes et al., 1995; Wolf and Soldo, 1994). The utilisation of leisure time for caring purposes has an effect on the wellbeing of the carer, affecting the carer's ability to relax, maintain social/personal relationships with others and perform other everyday tasks such as cleaning and shopping which can in turn result in feelings of resentment and isolation (Barnes et al., 1995). The adoption of the carer identity replaces aspects of the former identity, such as leisure activities which is not always welcome and can lead to further stress and burden. This is disputed by Ettner, (1996) who identified that providing care reduced hours worked in employment, but only for women providing care to parents who lived separately from them.

Seay, (2010) suggests that the female carers who also undertake paid employment would benefit from health insurance schemes that cover elderly parent care as well as children, and that flexible working arrangements are provided by employers to allow for the care of elderly relatives, as it is given for childcare. This is not supported by Starrels, Ingersoll-Dayton, Neal and Yamada, (1995) who found that family-friendly policies were associated with less care giving and that there were few differences in caregiving between the genders (of the carer). Certainly, the findings of Starrels et al., (1995) contradict somewhat the results of the study by Barnes et al., (1995) and support Ettner, (1996). This study found that daughters without employment were more involved in caring for elderly parents than those in employment. However, this may well be because the need of the parent was to such a degree that it necessitated more hours of caring than could be provided whilst in employment. The study also found that daughters who had previously been in employment and then terminated it to provide care were the group in greatest need of

caregiving support. This could potentially be for the aforementioned reason, feelings of isolation and stress (Barnes et al., 1995) from leaving the often socially interactive world of work, feelings of resentments from terminating or postponing career progression and an underestimation of the magnitude of the caring need. The adoption of the carer identity may progress to such a degree that it replaces the former self-identity of the carer (of which employment may be a large part) without any desire for their identity to change, resulting in grief for the lost identity and the aspects that made it such (such as employment).

Starrels et al., (1995) findings are challenged to an extent by a study more recently conducted in, 2006 by Henz. This study examined job characteristics and family configuration and assessed the impact they have on informal care. The study found that job flexibility was not an important aspect in the decision to care, or to continue to provide care, but did find statistically significant correlations between women of lower socio-economic class and the likelihood of leaving the labour market. This is not supported by the Carers UK, 2018 State of Caring Survey which suggested that carers juggling their caring role with employment desire a greater understanding from their employers. UK carers require employers that foster a caring workplace culture which is formally supported through carer-friendly policies such as carer networks, flexible working arrangements and informed and sympathetic managers (Carers UK, 2017). This is supported by Plaisier, Broese Van Groenou and Keuzenkamp, (2015) who found that a carer's ability to be in paid employment depended on the level of caring burden they had. They also confirmed the importance for carers to work for a knowledgeable and supportive organisation, with supportive colleagues and supervisors. Henz, (2006) disagrees however and concludes that *"flexible working hours are no panacea for the strains of combining family obligations with paid work"* (Henz, 2006 p.412).

A number of researchers have examined the effect of employment on the amount and quality of informal care provided, but have struggled to reach concurrence:

> That there is no completely consistent account of the
> relationship between caring and employment could be
> because of different national backgrounds and the different
> study designs, and also because of restrictions in terms of

carer's ages, the relationship with dependents, or the types
of care provided.

Henz, (2006 p.415).

The potential effects of employment on caring were considered in a study by
Carers UK in, 2017. The report found that the effects are threefold; firstly some
carers have to reduce or terminate paid employment to meet their caring
responsibilities; secondly attempting to maintain employment whilst working can
be extremely problematic for carers and thirdly as demographics change, carers
are more likely to genuinely need paid employment for financial reasons.

Carers UK, (2017) suggest that the biggest problem facing the UK population is
the former:

> The evidence is that carers give up work to care. Polling
> carried out by YouGov on behalf of Carers UK suggests that
> over 2 million people have given up work at some point to
> care for loved ones and 3 million have reduced working
> hours

Carers UK, (2017 p.3)

The cost of informal care must also be considered in a wider societal context.
Carers UK, (2017) publicised concerns regarding the true cost of caring when
carers have to reduce or terminate paid employment. These costs include costs
to employers:

> The Corporate Leadership Council estimates that the
> cumulative costs to employers of an employee leaving work
> are equal to an employee's last salary, while Hay Group
> suggests it could cost anywhere from 50-150% of their salary

Carers UK, (2017 p.3)

The loss to the labour market of carers in employment also results in a shortage
of workers, both skilled and unskilled in the job market which may impact the
UK's global competitiveness (Age UK, 2012). There are further implications for
private pension provision and the long-term state benefits bill (Age UK, 2012).
In fact, Age UK, (2012) (in collaboration with the London School of Economics)
confirmed an estimated £5.3 billion lost from the economy due to carers
reducing or terminating paid employment.

The employment status of carers has been shown to be a contentious subject with academics failing to reach concurrence on the exact effect that employment has on caring. Whilst the benefits of employment policies designed to support informal carers are arguable, the cost to the wider economy of carers leaving employment to provide informal care cannot be contended. Questions also remain regarding the loss of employment identities with the onset of caring, how the changes occur and whether these changes are welcomed which will be addressed later in this thesis.

2.2.7. Social and demographical differences

The marital status of carers has been found to affect the amount of informal care provided to others. More informal care is provided by sons and daughters that are not married than those that are (Bracke et al., 2008; Laditka and Laditka, 2000; Himes, Jordan and Farkas, 1996; Stoller, 1983). In fact, Stoller, (1983 p.856) stated that *"adult children who are married provide, on the average, over twenty hours less help than those who are not married"*. The competing, multi-faceted demands on time and resources which being married lends itself to, results in fewer hours available to provide care as more married individuals also have children, paid employment and other demands (Laditka and Laditka, 2000; Stoller, 1983). The competing demands of marriage result in the caring burden falling disproportionately on unmarried children (Eriksen and Gerstel, 2002) because they have fewer familial identities (such as wife, Mother etc.) to maintain and so are able to absorb the carer identity to a greater degree.

A further consideration into the provision of informal care is the socioeconomic class and educational achievement of both carer and cared for. Care recipients with lower educational achievements are more likely to require informal care from adult children and that adult child is usually female (Checkovich and Stern, 2002).

Lahaie, Earle and Heymann, (2013) suggested that female caregivers, caregivers with poorer educational attainment and both first and second generation immigrants were more likely to experience poor working conditions and so experience greater problems in providing informal care (the study

considered employment aspects such as flexible working hours, the ability to take a personal telephone call at work, paid time off etc.) Although the study highlighted differences, explanations for these differences were not offered and further research to investigate these differences were suggested by the authors, particularly in other countries with different demographics in terms of educational attainment and immigration.

An additional factor in who provides informal care is the socio-economic class and general wealth of both the carer and care recipient. Rubin, Denson, Kilpatrick, Matthews, Stehlik and Zyngier, (2014 p.196) confirmed that social class is based on *"an interaction between people's social, cultural and economic background and status"* and, together with variables that are socially constructed (such as fashion choices, accents etc.) have a profound effect on how individuals behave as well as their attitudes, preferences and values. Dean et al., (2014) conducted qualitative research with participants of middle socio-economic classes to understand the transitional role of the family carer, but work has yet to focus on this role in deprived areas with participants of lower socio-economic classes. Laditka and Laditka, (2000) suggest that more affluent adult children are more likely to purchase formal caring services for their parents, rather than provide them themselves. Affluent adult children do not have the physical necessity to adopt the carer identity themselves (although they may actually wish to) and so are able to maintain their previous identity despite the care needs of their parent changing. This suggests that the likelihood of an adult child providing informal care has a direct correlation with the wealth of the adult child. This is challenged by Mathur and Moschis, (1999) however who found that the amount of care provided by family members decreased as income decreased. This suggested that in different societal classes, there exists different norms of what constitutes a socially acceptable level of care, as well as different abilities to provide that care.

This section addressed the question 'who are carers?' and has confirmed that the extent to which carer identity is absorbed by the individual providing care is dependent on a number of different factors including gender, relationship to the care recipient, residential arrangements, marital status, employment status and social class/educational achievement. The identity change to carer can occur by

degrees and is a transition which can occur gradually over time. However, research has yet to confirm how this transition occurs, what motivates the transition or the effect of the transition on those involved.

The research has illustrated that there is no such thing as a typical carer. Although extant research has identified similarities in the gender of carers and their relationship to the care recipient, much contradiction exists in other aspects considered in the identification of carers and how they provide care. Dwyer and Coward, (1991) suggest that future research should concentrate on the understanding of the carer perspective, rather than their identification:

> Future research should now concentrate on developing a better understanding of the dynamic that leads to such differentials and the theories that account for such behavior…The greatest challenge in caregiving research now consists of documenting and describing those factors and interpersonal dynamics that influence the composition, configuration and behaviors of the helping network that provide care.

> Dwyer and Coward, (1991 p.S267 and S268)

The next section therefore considers the question 'what affects carers?' Building on existing knowledge of who carers are, the section will consider how carers fare in their provision of caring and what affects their experiences and behaviours. The interpersonal dynamics of caring will be considered to understand carers and provide a basis for this research study.

2.3. What affects carers?

This literature review has so far defined the issues relating to care in the UK and has considered carers as a group. The next section considers carers as individuals – their experiences, the reasons why they provide care and how caring affects them as people, their lives and their relationships with others.

2.3.1. Geography

An important aspect to a carer's ability to provide care relates to their physical location in relation to their care recipient, other family members and amenities and services. Gibson, (1992) suggested that there exists a widespread myth that older people are isolated from their families, and that this is simply not the case. In Gibson's (1992) book on the emotional lives of older people, Gibson identifies that the majority of older people live in close proximity to their families and that most had had contact with a family member in the previous 48 hours. However, other research suggests that carer relationships and geographical proximity are much more complicated and deserving of much closer scrutiny.

In, 1994 a study was conducted by Lawton et al. which investigated the relationship between levels of affection and frequency of social contact between adult child and elderly parent. The authors cite Connidis and Davies, (1990) to state; *"Geographical proximity should also encourage emotional intimacy insofar as it facilitates social contact and increases opportunities for shared experiences"* (Lawton et al., 1994 p.59). The study demonstrated an association between frequency of contact and level of affection in the Mother-child relationship, but not in the Father-child relationship, and that this was affected by geographical proximity. This suggests that the relationship between affection and contact frequency is gender-specific and raises further questions as to why this may be the case. The study also demonstrated that parental divorce had a significant impact on both levels of affection and frequency of contact, and found that family solidarity could be passed down through the generations and so included the influence of Grandparents as a measure of solidarity. Importantly, the study found that geographical proximity was inter-related with other aspects pertaining to the family structure. Adult children were found to be more likely to live close to the elderly parent (within 1 hour) if they had children

of their own (Lawton et al., 1994) and home owners were more likely to live close to elderly parents than renters (Lawton et al., 1994).

Campbell and Martin-Matthews, (2003 p.S354) suggested that "g*eographical distance is a significant predictor of care involvement"* in terms of both frequency and quality of care contacts. This is supported by Hiedemann and Stern, (1999) who found that the closer adult children reside to their elderly parent, the more they are valued as care providers.

Motivations to provide or not to provide care included the suggestion that geographical distance between carer and care recipient can be used as a legitimate excuse for limited filial care provision by sons and daughters (Campbell and Martin-Matthews, 2003). The fact that adult children may live a considerable distance from their parent can lead to minimal uptake of the carer identity because the inception of informal caring may not affect those adult children on a daily basis. The study by Campbell and Martin-Matthews, (2003) showed that increased geographical distance made the practicalities of providing informal care to a family member challenging, particularly when large distances were involved, which could then be used as a reason not to provide care. However, some potential carers may see geographical distance as a barrier to the willing provision of filial care and therefore attempt to address it, by relocating closer to the care recipient (Campbell and Martin-Matthews, 2003).

Hamon, (1992 p.94) also found *that "the strength of the relationship between enactment* [of caring tasks] *and affection* [between adult child and parent] *varies as the geographical distance between parent and child varies"*. However, the association highlighted by the study was not linear (the greater the distance, the less enactment and affection or vice versa). Hamon, (1992) suggested that this confirms the existence of specific optimal and therefore sub-optimal geographical distance between parent and child. Carer and care recipients who lived within 30 minutes of each other had a greater level of affection and positive enactment of caring tasks as well as those that lived between 2 and 6 hours apart, however affection did not have an impact on enactment when carer and care recipient lived between 30 minutes and 2 hours apart, or over 6 hours apart (Hamon, 1992). This suggests that the quality of the relationship between

carer and cared for is affected by geographical distance and that the carer and care recipient "may lose awareness of each other" (Hamon, 1992 p.94) if the geographical distance between them is too great.

A possible explanation of these findings may include the fact that residing over 6 hours apart may ensure that physical contacts between carer and cared for are less frequent, but may also potentially result in a greater number of remote contacts (such as telephone calls etc.) Gilleard and Higgs, (2005) state that there has recently been a change in the emotional closeness of adult children and their parents due in part to increased physical distance between them. They recount that there has been a shift in the nature of kinship which has resulted in less emphasis on physical contacts and a greater emphasis on keeping in touch (Gilleard and Higgs, 2005).

Geographical proximity between carer and cared for however, is not the only consideration in terms of geography and informal care provision. The location of the care recipient, the local community, the period of continued residence and the emotional attachments to a home or an area also have an important role to play in the life-course of the care recipient. Gilleard and Higgs, (2005) suggested that care recipients are more inclined to remain in homes for longer as their age increases and health decreases: "*The longer an individual lives, the less likely he or she is to move"* Gilleard and Higgs, (2005 p.125).

The strength of social bonds in the local community can be an additional reason why care recipients are reluctant to move home. This, coupled with an emotional connection to the bricks and mortar of the house can make relocation emotionally fraught (Gilleard and Higgs, 2005). However, the age in place theory found that those elderly residents who remain in their existing location often find themselves with less social bonds in the local community than expected. Gilleard and Higgs, (2005) confirmed that this is because residents of communities exhibit and occupy similar characteristics which allow them to act as a community. The similarities which upheld the social bonds of previous decades result in an increasingly elderly community, competing for similar resources and diminishing in size, to be replaced eventually by an alternative community with new and alternative social bonds. Gilleard and Higgs, (2005) suggested that for this reason, the ageing in place grow increasingly likely to be

"bussed into the ascribed communities of the fourth age" (Gilleard and Higgs, 2005 p.129), essentially moved to specific elderly communities, into residential care or moved geographically closer to those that provide informal care.

There has also been a shift from care provided by adult children to that care being primarily provided by spouses which has resulted in a slackening of the emotional bonds between adult children and parents and a greater geographical distance between the two parties (Gilleard and Higgs, 2005). Increased spousal caring has led to greater emphasis on the spousal relationship; a prioritisation of the spousal relationship, its bonds, emotional strengths and stability above other familial relationships which may jeopardise the relationship between elderly parents and their adult children (Gilleard and Higgs, 2005). The resultant lessening of the emotional bonds of the parent-child relationship can make adult children more likely to geographically relocate which may cause further detriment to the parent-child relationship and impact the provision of informal care (Gilleard and Higgs, 2005). Increased geographical distance between care recipients and adult children may mean that they are less likely to transition their self-identity to that of a carer because the inception of informal care need has changed their routines and affected their life to a lesser degree. This is exacerbated when a spouse exists who may potentially be better placed to absorb the carer identity, allowing the adult child identity to remain unaltered.

2.3.2. Rural and urban differences

The demographics of the place of residence have also been investigated for effect on carer experience - differences in this experience have been highlighted in carers who reside in rural and urban areas (Creese, 2003).

The International Longevity Centre (ILC) conducted research on behalf of DEFRA who produced the, 2013 Rural Ageing Research Project. The research showed that

> The fastest rate of UK population growth is among the oldest age groups (aged 85 and older). The older age group is also growing faster in rural areas. There is also evidence that older populations pose disproportionate challenges for rural areas compared to their urban counterparts.

> ILC, (2013 p.3)

In this research, it was found that older residents in rural areas suffered from growing social isolation, loss of local services and high costs of living, supporting research completed by Gilleard and Higgs, (2005). Service delivery challenges included lower economies of scale, higher per-capita costs and increased costs of travel (ILC, 2013). Lack of transport access in rural areas was found to reduce social and civic participation and limit engagement with health services. Failure to plan ahead and understand preventative care was also shown to result in elderly rural residents only seeking health assistance when they suffered from severe health problems (ILC, 2013) and elderly residents of rural areas were more likely to make do and fend for themselves; were more conscious of being a burden; had limited awareness of relevant services and were afraid of external actions if they revealed a need (ILC, 2013).

Phillimore and Reading, (1992) considered whether health outcomes were related to urban or rural residence. The study showed that health measures were more related to levels of wealth than rurality but that this was not the case in areas of very remote rurality. The link between wealth and caregiving has also been demonstrated in the previous section, suggesting that levels of wealth, rurality and caregiving may be inter-related.

There is limited research available regarding the explicit effect of rural versus urban dwelling in terms of caregiving. One study by Creese, (2003) investigated the experience of caregivers for dementia patients and concluded that differences between rural and urban caregivers may well exist but called for further research into the topic.

Indeed Tommis, Seddon, Woods, Robinson, Reeves and Russell, (2007 p.743) agreed; *"Rural and urban differences in the effects of care-giving are not well documented".* It is accepted that differences did indeed exist in terms of informal care and level of rurality and further research to investigate these differences is needed (Creese, 2003; Tommis et al., 2007). Heenan, (2008) found that care-giving in rural areas had a greater basis on cultural expectations and norms, particularly for female carers. Heenan, (2008) discovered that in rural areas, formal services were resisted to a greater extent than in urban areas as a direct consequence of these cultural expectations which viewed outside help as a failing in rural areas. Rural families took pride in caring for their elders, but due

to their cultural norms, found it difficult to recognise the carer label of identity. In fact, Heenan, (2008 p.856) considered this label as *"meaningless"* in rural areas of the study as caring was considered a feature of normal family life, rooted in the perception of reciprocal care of family members.

A further consideration of rural versus urban caring is differences in financial burden. Ehrlich, Bostrom, Mazaheri, Heikkila and Emami, (2015) found significant differences in financial burden between urban and rural residents. Rural residents were found to report greater financial burden in comparison with urban residents, due to limitations of available services and greater costs associated with utilising amenities. Urban caregivers however, reported significantly more feelings of isolation than rural caregivers due to difficulties in getting help from their wider family and limitations of community support (Ehrlich et al., 2015). This did not support Lucke, Russell, Tooth, Lee, Watson, Byrne, Wilson and Dobson, (2008) who identified no differences in the utilisation of services between urban and rural elderly populations. In fact, Lucke et al., (2008) considered formal services to be under-utilised by both elderly populations.

The objective of the 1990 study by Dwyer and Miller was to design a conceptual model to explain primary caregiver stress and burden in rural, small city and urban examples. The study extracted data from the, 1982 National Long Term Care Survey and the National Survey of Informal Caregivers. The study was based on the premise that the provision of informal care can have a detrimental effect on the carer, and that this differs according to whether the carer and care recipient reside in an urban or rural location. The results of the study confirmed the existence of differences in the caregiving relationship in urban and rural areas, but not in all considered areas (Dwyer and Miller, 1990 p.35). The results were *"unclear"* in terms of carer burden and stress differences according to rural/urban location:

> These findings do not support the notion that caregiving-related characteristics will conform to a residential continuum.

> Dywer and Miller, (1990 p.35).

The study did identify the greater importance of informal carer community networks in rural areas and Dwyer and Miller, (1990) suggest that this may support the notion that an informal care network does not replace the primary caregiver but acts as supplementary resource in times of greater need. The carer identity is therefore more likely to be assumed in rural areas, but the identity transition and maintenance is supported by informal networks local to that rural region. This is supported in part by Byrd, Spencer and Goins, (2010) who found substitution of informal care networks in the place of formal care services in rural areas and theorised that the reality of fewer services in rural areas is not transparent in research studies because the caregivers learn to adapt through the use of informal carer networks and so actually feel no greater burden or stress (Byrd et al., 2010). Pei and Tang, (2010) identified issues with local and national state or Governmental efforts to improve aged wellbeing, because of an absence of link-up between these large initiatives and local community development networks in rural areas. Dwyer and Miller, (1990 p.36) concluded that *"further investigation is needed to provide a fuller understanding of these issues"* and considered their findings in terms of the provision of policies for caregivers. The differences in carer experience and characteristics according to rural/urban residence are too notable for carer policies to be applied in a one size fits all manner and policies should be tailored, taking into account these differences (Dwyer and Miller, 1990).

Carers in rural areas may be at a disadvantage to their urban counterparts because access to services is logistically more problematic and fewer services are actually available. (Byrd et al., 2010; Dwyer and Miller, 1990; Goins, Spencer and Byrd, 2009; McKenzie, McLaughlin, Dobson and Byles, 2010). However, despite the increasing problems associated with an ageing population, there has been limited research completed on the subject of rural/urban differences in access to formal services related to caring (McKenzie et al., 2010) and the inconsistencies in definitions of related key terms has implications for findings in the research conducted to date (Goins et al., 2009). Inconsistent evidence of rural-urban differences in care provision requires further research to address this lack of clarity (McKenzie et al., 2010):

> In the current environment of rapid population aging, there
> was surprisingly little literature on the topic of this

review…there is too little evidence comparing urban and rural carers to inform clinicians and policymakers. More good-quality research is urgently needed.

McKenzie et al., (2010 p.143)

As well as consideration of the wider external factors that affect carers, reflection is also necessary to identify aspects which are personal to individual carers, such as the reasons why they provide that care, and how they feel about doing so. The adoption of carer identities in rural and urban areas requires further research to understand any potential differences in experiences.

2.3.3. Motivations to care

The propensity of an individual to provide care is dependent on many factors and includes nuances within the interpersonal relationship between the potential carer and care recipient. Emotions such as love and affection can motivate an individual to provide care whilst moral rectitude involving feelings of duty and obligation can also act as incentives to provide care. The next section examines care motivators and considers the effect they have on the carer, care recipient and the associated relationships of those involved.

The act of providing informal care is based on a special affection or concern for the care recipient and always involves personally relating to another person according to Leira, (1994).

Wærness, (1982), cited in Leira, (1994) states that

> Care originates in a relationship involving (at least) two human beings. The caregiver shows concern, worry, consideration, love and devotion for the person receiving care. The one who needs care is precious to the one who is caring and, when the cared for suffers, the one caring will also suffer and see to it that the pain or discomforts are relieved.
>
> Waerness, (1982) in Leira, (1994 p.188)

The definitions provided by Wærness, (1982) provide a positive, emotive note to the caring concept based on affection and concern, and Leira, (1994) claims that 'caring for' is closely related to 'caring about'. Leira, (1994) also reasons that, to be a carer, there must be a *"willingness to be personally obliged by the*

social norms that demand that very helpless people be cared for" (Leira, 1994 p.190). Therefore, simply caring about an individual will not necessarily instigate the provision of informal care alone; a mix of affection and obligation is necessary to inspire informal care, there must exist a willingness to alter self-identity for the pure purpose of assisting another person.

This idea of a prerequisite level of affection for successful caring relationships is supported by Engster, (2005) who described a proportional relationship between the level of affection the carer feels for the care recipient and the 'quality' of the care provided. In fact, Baikie, (2002) suggests that it is not just the level of affection felt, but the wider quality of the relationship between carer and cared-for prior to the commencement of caring that dictates potentially how much carer burden will be experienced. However, affection is not the only motivator for the provision of informal care. The overarching feeling of being needed as well as the obligation and duty care givers feel towards the care recipient is the biggest motivating factors to provide informal care (Oudijk et al., 2011). Informal care *"is developed as an ethic or moral orientation, emphasising the welfare of the collectivity as much as that of individuals"* (Daly, 2002 p.253) however, the division of this obligation is not necessarily shared equally between family members and is felt more keenly by females and by adult children with only one surviving parent (Stein, Wemmerus, Ward, Gaines, Freeberg and Jewell, 1998). The perceived burden of the obligation to care is complicated and depends on a number of factors including the health of the care recipient (Cicirelli, 2000) and also the strength of the relationship between the parent and adult child (Stuifbergen et al., 2008). This suggests that love and affection, duty and obligation as motivators to provide informal care are actually interrelated (Bengtson and Robert, 1991).

Bengston and Robert, (1991) produced a model of association to represent the caring relationship construct: affection; consensus; resource sharing; strength of family norms; and opportunity structure for interaction. The study confirmed that normative solidarity (obligation and expectation) was positively related to levels of affection and hence association, effectively improving the care relationship. This is supported by Stuifbergen et al,. (2008), Engster, (2005) and Cicirelli, (2000) and suggests that the greater the obligation felt by filial carers, the

greater the hours of care provided and the closer the relationship between carer and care recipient (White-Means and Hong, 2001) - that it is perceived obligation and affection which ignites a transition in self-identity towards becoming a carer.

The idea of reciprocity in caring has been investigated in a number of studies (Bengtson and Roberts, 1991; Caputo, 2002; Silverstein et al., 2002). The study by Silverstein et al., (2002) considered reciprocity and suggested that:

> Parents' transfers of sentiment, time and financial assets to their adolescent/young children affect the children's propensity in middle age to provide social support to their aging parent
>
> Silverstein et al., (2002 p.S3)

This is supported by Caputo, (2002) who investigated motivational models of human behaviour regarding exchange and altruistic theories. The study investigated adult daughters caring for elderly parents and whether they acted as rational agents (motivated by potential personal gain) or as rational actors (adhering to social norms of filial responsibility). The study extended work completed by Bengtson and Roberts, (1991) on intergenerational solidarity and concluded that daughters acted as rational actors operating from accepted social norms, but that this stems from a sense of obligation – in reciprocity for assistance received earlier in life. This supports both Bengtson and Robert, (1991) and Silverstein et al's., (2002) theories regarding exchange theory and reciprocity in intergenerational caring relationships.

Raschick and Ingersoll-Dayton, (2004) also proposed that the adult child providing care for the elderly parent is doing so in reciprocity for the care he or she received in the past. This reciprocal exchange of caring continues throughout the caring relationship and often involves financial reward (gifts of money or assistance with bills) and inter-relational exchanges, such as the care recipient providing some childcare to the adult child's own children which has positive effects of reducing stress and burden for the carer and increasing wellbeing of the care recipient (Dwyer, Lee and Jankowski, 1994; Raschick and Ingersoll-Dayton, 2004). Del Rio-Lozano et al., (2013 p.1509, 1510) agreed and identified a "*large effective component*" in caring expectations due to a "*sense of debt*" in parental care which was not present for carers occupying

other familial roles. The benefits of reciprocity as described by Raschick and Ingersoll-Dayton, (2004) can only apply however with the tacit acknowledgement of both parties that each has something to give the other. Lee, (1985) stated that it is psychologically uncomfortable to be the dependent party in an exchange relationship and Dwyer et al., (1994) agreed that this dependence can be construed as a power imbalance in the relationship. This may result in the care recipient feeling guilty, powerless and stressed if they are unable to participate in the reciprocal relationship, which may then be compounded if the level of care required is essential for daily living (Dywer et al., 1994). In essence, inability to reciprocate can have a detrimental impact on the carer-cared for relationship:

> It is the inability [of the care recipient] to reciprocate, rather than the need for assistance [which] undermines the morale of the older person.

> Stoller, (1985 p.341)

Dwyer et al., (1994) argued that reciprocal caring via exchange theory does not affect the wellbeing of the care recipient but does have a significant impact in reducing the burden experienced by the caregiver (which is rooted in the competing demands of family life - Soldo and Myllyluoma, 1983) as reciprocity provides a potential vehicle to reduce total carer obligations (e.g. by providing financial ability to outsource domestic cleaning tasks etc.) This may in turn give the carer more time to provide further caregiving duties etc. (Dwyer et al., 1994). Lee and Ellithorpe, (1982), McCulloch, (1990), and Mutran and Reitzes, (1984) all concurred that reciprocity in caring does not affect the wellbeing of the care recipient but did not consider the wellbeing of the carer. Mancini and Blieszner, (1989) however, claimed that the reciprocal relationship is in fact weighted in favour of the care giver; offering great benefits for the wellbeing of the carer but offering little value to the care recipient. In spite of this, Mancini and Blieszner, (1989) argued that this relationship can be inverted by financial hardship and/or serious health failings whereby the benefit to the care recipient outweighs that of the carer.

Caring is 'doing' – giving care confirms the communal nature of family based on a need, rather than payment or exchange (Barnhart et al., 2014) however other

research has suggested that financial gain can be a powerful motivator to the provision of informal care.

Checkovich and Stern, (2002) found that the promise of future bequests affected the caring relationship and that an "exchange relationship" whereby the parent (care recipient) perceived the bequest as long term financial reimbursement for the care provided by the adult child (carer) was apparent. The same could not be evidenced from the perspective of the adult child, providing care on the understanding of a future bequest, however Checkovich and Stern, (2002) questioned the potential for dishonest responses due to the highly moralistic nature of the enquiry. White-Means and Hong, (2001) also examined motivating factors in filial caring, specifically whether it was altruism or potential bequest that led to commitment to care for. Their findings confirmed that the incentive of a bequest may 'dominate' an adult child's motivation to provide care (White-Means and Hong, 2001). This therefore has important potential implications for public policy:

> If potential family caregivers provide adequate caregiver support with an expectation to receive some sort of personal gain, public policy strategies that provide compensation (e.g. tax credits or direct financial rewards) may be effective.

> White-Means and Hong, (2001 p.365)

Understanding motivations to provide informal care is problematic as they often consist of a number of factors such as duty, affection, reciprocity and even future bequests, acting simultaneously. The consideration of motivation in informal care relationships is an important factor however, as reasons for providing care are linked to roles and responsibilities within family units, and therefore familial identities. The acting (or not) upon this motivation to provide informal care also has an impact on the personal wellbeing of the carer and the different motivations to provide care can affect the transition between previous identity and carer identity, or even whether any transition occurs at all. However, motivations to care and their potential effect on identity have not been fully researched to date.

2.3.4. Loneliness and isolation

Elderly people often suffer from loneliness and social isolation because relatives do not have enough time to provide adequate social contacts and the number of close friends they have tends to decrease (Ongun, Guder and Demirag, 2016*) and "social interaction is an innermost human need at any age. A lack of social contact results in social isolation and relative loneliness"* (Ongun et al., 2016 p.36). Carers UK recognised the increasing issue of loneliness and social isolation in the aged and commissioned the Jo Cox Loneliness Commission, 2017 to investigate the phenomenon. Carers UK (Jo Cox Loneliness Commission, 2017) identified key differences between the two phenomena and suggested that a distinction between the two must be noted as each has distinctive effects on the wellbeing of the sufferer. Victor, Scrambler and Bowling, (2005) define social isolation as the difference between desired and experienced social contact and loneliness as a feeling of lack of companionship. The 2017 Carers UK State of Caring Survey considered the opinions of over 7000 UK carers and identified a number of generalisations as to why carers suffer from limited social contacts and feelings of loneliness. These included lack of time and energy for social contacts, changes in lifestyle resulting in a feeling of being different to old friends and old lifestyles, lack of financial resources to indulge social contacts and limited ability to leave their caring role for the duration of a social contact. The self-identity of the carer may change because the aspects that formulated previous identity (such as work, hobbies and friends) have been lost. The survey also revealed that loneliness and social isolation was more likely in carers who had been in their caring role for over 10 years and that the dynamic relationship between the carer and cared for, (where old relationships are relinquished and replaced with the carer-cared for dyad) increases levels of loneliness (Carers UK, 2017). This is supported by Cormac and Tihanyi, (2006) who also found that the onset of care could result in the exclusion of other roles and the associated loss of other relationships – a negative change in the self-identity of the carer. Ongun et al., (2016) also suggested that loneliness may be more common than reported due to a stigma attached to admitting sufferance from continuous loneliness.

Academic research into loneliness and isolation has also been conducted on UK populations (Luanaigh and Lawlor, 2008; Steptoe, Shankar, Demakakos and Wardle, 2013; Victor et al., 2005) and has largely focused on the links between loneliness and general health, (both physical and mental) of the cared-for, rather than the carer.

A literature review conducted by Luanaigh and Lawlor, (2008) assessed loneliness and the health of older people (irrespective of carer status) and found strong associations between loneliness, isolation and depression. The review also found that loneliness had a significant impact on a variety of physical health measures (such as blood pressure, immune stress response, sleep patterns etc.) These finding are supported by Steptoe et al., (2013) who surmised that loneliness and isolation are associated with increased risk of mortality among older people. Gibson, (1992) suggested that research considers all aspects of emotional wellbeing rather than just loneliness and isolation and confirmed that:

> It is the emotional health of older people, their positive perception of themselves, that is of primary importance in maintaining their continued wellbeing.
>
> Gibson, (1992 p.55).

Emotional wellbeing is a subjective concept, taking into consideration loneliness and social isolation, but not exclusively; nor does wellbeing merely relate to the wellness of the body and mind, moreover, wellness should be considered holistically (Gibson, 1992).

Although previous research has considered the physical effects of social isolation and loneliness, other research has been completed to consider loneliness as a concept in itself. Three loneliness pathways (Victor et al., 2005) were identified to model loneliness and its origin and were identified as 'continuation of long-term loneliness', 'late-onset loneliness' and 'decreasing loneliness' (Victor et al., 2005). The author expressed these pathways to loneliness as being very different for the individuals experiencing them and called for policy-makers and third sector industries to acknowledge these differences in dealing with old age loneliness. The author did not distinguish

however, between loneliness experienced by carers or care recipients – a consideration deliberated by Carers UK, (2017).

Although research has been conducted on the effects of loneliness and the types of loneliness experienced, Carers UK, (2017) conducted a survey to consider methods for dealing with loneliness and social isolation in carers. They identified breaks from caring to be the most valuable treatment to reduce the negative consequences of caring (such as loneliness and isolation) which could include formal breaks involving respite care, or informal breaks with the addition of temporary familial care resource. Carer breaks may allow the carer to temporarily suspend their self-identity as a carer and pick up aspects of their previous identity (such as hobbies). However, carer breaks were found to be complicated endeavours which involved a number of considerations such as the financial burden of replacement carers, availability of suitable carers, stress and anxiety for the care recipient etc. (Carers UK, 2017) which often increased stress and anxiety in the carer to such an extent that the arrangements needed to take a carer break outweighed the benefit of the break itself (carer burden is discussed in greater detail in the next section).

The ability for carers to take a break from their duties is often dependent on their ability to be confident in the care recipient's well-being whilst the break is taken. Carer breaks may include holidays away from the caring target for days at a time but may also involve shorter breaks of even a few hours. Developments in technology have been applied to caring in terms of physical health, such as the 'TeleHealth' system used to monitor the health of chronic disease patients (Koch, 2006) and personal wireless sensor-based network solutions such as 'Lifeline' (Steele, Lo, Secombe, Wong, 2009) used to alert a designated individual of a problem (generally used for falls) which are now commonplace in the UK. Mattresses with sensors to alert an individual to a lack of pressure (and therefore potentially a fall out of bed) are also beginning to be used frequently in the homes of the elderly and infirm (Yu, 2008). Thus, technological advancements have come some distance in providing comfort to families in ensuring the well-being of their elderly loved ones (Riche and Mackay, 2010), particularly in the assistance of providing peace of mind for short term carer breaks. These technological advances allow carers to take a

break with greater ease and to be made aware of potential problems without actually having to be physically situated with the care recipient. However, Riche and Mackay, (2010) questioned whether these remote monitoring system benefit both parties in the caring dyad:

> Monitoring approaches focus on supporting the caregiver;
> the elderly benefit only indirectly and only in limited ways.
>
> Riche and Mackay, (2010 p.74)

Although designed to assist in the prevention of loneliness and social isolation of the carer, the provision of 'technological caring' may potentially lead to less social contacts and increased loneliness and isolation for the care recipient (Riche and Mackay, 2010), as the carer can provide a certain amount of care at arm's length. Ongun et al., (2016) however, suggested that technologies and in particular media forms are crucial to the prevention and/or minimisation of loneliness in the elderly: *"non-interactive media forms such as print media, radio, television and computer still befriend the old"* (Ongun et al., 2016 p.44)

Carer loneliness and social isolation are well-known phenomena (Carers UK, 2017; Riche and Mackay, 2010) however are not the only negative consequences that the provision of informal care may cause. The next section considers the negative consequences of providing care on the carer, known as carer burden: *"Caregiver burden is an all-encompassing term used to describe the physical, emotional and financial toll of providing care"* (Parks and Novielli, 2000 p.2613).

2.3.5. Carer burden

> Caregiving has all the features of a chronic stress
> experience: It creates physical and psychological strain over
> extended periods of time, is accompanied by high levels of
> unpredictability and uncontrollability, has the capacity to
> create secondary stress in multiple life domains such as work
> and family relationships and frequently requires high levels of
> vigilance.
>
> Schulz and Sherwood, (2008 p.105)

Care-giver burden has been considered by researcher in a variety of specific situations, including informal carers of Alzheimer patients (Yu, Wang, He, Kiang

and Zhou, 2015), informal carers of mental health patients (Reine, Lancon, Simeoni, Duplan and Auquier, 2003) and even informal carers of children with cerebral palsy (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu and Wood, 2005), however all those researchers agree – informal caregiving is not easy for the carer and negative consequences for the carer frequently exist:

> This [caregiving] experience is commonly perceived as a chronic stressor and carers often experience negative psychological, behavioural and physiological effects on their daily lives and health.
>
> Bevans and Sternberg, (2012 p.398)

In fact, Schofield, Murphy, Herrman, Bloch and Singh, (1998) discovered that levels of carer burden were also dependent on the illness of the care recipient – specifically physical compared to mental impairment:

> Carers of physically impaired relatives reported better health, greater life satisfaction, and less overload, negative affect, family conflict, anger and resentment than carers of those with intellectual impairment, whether labelled as dementia or not.
>
> Schofield et al,. (1998 p.355)

The nature of providing care is dynamic – the health of both the carer and cared for is changeable and *"caregivers are often faced with multiple concurrent stressful events and extended unrelenting stress"* (Bevans and Sternberg, 2012 p.398). O'Shaughnessy et al., (2010) agreed that carers are subject to constantly shifting situations which result in uncertainty and feelings of losing control of their own lives. This ultimately manifests in the eclipse of their own wants and needs and their sense of self-identity becomes subsumed by the identity of carer (O'Shaughnessy et al., 2010).

Informal carers often have multiple roles to manage and are rarely 'just carers' – even when no formal employment is held. Carers still carry other relationship identity labels (such as Wife and/or Mother) and have other tasks to complete external to their caring role - the carer may be unable to adopt the carer identity to the extent they may wish to do so, which can cause further stress. In, 1999 Couch et al. considered the allocation of household time and money resources

in families (in which the elderly parent did not co-reside with the adult children) and the four demands on them; time spent in paid work; time spent providing informal care; time spent performing housework and monetary transfers from adult children to elderly parents. The research identified that families which had greater income were more likely to rely on *"cash transfers"* than *"time transfers"*, (Couch et al., 1999 p.219) effectively buying in care instead of providing it themselves to manage the demands of multiple roles. The researchers also predicted issues in the allocation of resources for younger families in the coming years because *"as the proportion of older individuals grows and life expectancy is extended, the potential demands upon resources of younger households are likely to increase"* (Couch et al., 1999 p.219) – the burden of multiple roles will be experienced for longer. This is particularly important when then effects of divorce are considered – divorced parents could result in up to four parental households competing for adult child family resources (Couch et al., 1999).

An article written by Stephens and Franks in 1999 considered the multiple roles (caring for an elderly parent, caring for children, being married and being employed) of female adult children carers and how this multiplicity affected their wellbeing. The article centred on the testing of three hypotheses; the *"Competing Demands Hypothesis"* whereby multiple roles compete for the individual's personal resources, often with negative consequences such as stress and anxiety; the *"Scarcity Hypothesis"*, embedded in the first, which assumes finite personal resources which are shared in differing proportions between multiple roles and the *"Expansion Hypothesis"* whereby multiple roles result in net gains of personal resource such as self-esteem, social gains and altruism (Stephens and Franks, 1999).

The study concluded that no single hypothesis could capture the true position of the individual as there was a propensity for the negative impact of one role to offset the positive impact of another. The study called for further research to develop a theoretical framework for understanding women who have multiple roles and recognised that competing roles may affect both the quality and quantity of care provided. The effect of multiple roles (and identities) on carer

burden is not well understood presently but has been identified as a contributing factor, however, carer burden can also be due to other causes.

Bevans and Sternberg, (2012) considered the effect of carer burden on the health of carers and found that the most obvious signs of carer stress included issues such as anxiety, depression, insomnia and loneliness. They found that the main contributing factors to carer burden were the necessity to modify their lifestyle (under duress), effectively being forced to alter their self-identity through circumstance. This was supported by Cormac and Tihanyi, (2006) who found that around half the carers they surveyed believed that their health was adversely affected by their role of carer, including *feeling "trapped, resentful, angry or upset and excluded from society"* (Cormac and Tihanyi, 2006 p.164). In fact, Aggar, Ronaldson and Cameron, (2011) found that *"anxiety and depression are the most common negative reactions as a result of providing care for a frail older person"* (Aggar et al., 2011 p.671) and that health was worse in carers who resented their caring role. Carers have little time to relax or take breaks from caring and carers tend to prioritise the health and social needs of the care recipient before their own needs, affecting their general wellbeing and health (Bevans and Sternberg, 2012). Essentially, the carer's self-identity may be changed against their wishes, they are consumed by their caring role and can no longer find the time to pursue the aspects of their life that previously reinforced their identity, such as hobbies or maintaining relationships outside of the caring role. Chambers, Ryan and Connor, (2001) confirmed that social support is an important factor in maintaining psychological wellbeing in carers and that all too often:

> Caregivers… can become isolated from social supports due to responsibility and confinement and become at risk of increased stress and depression.
>
> Chambers et al., (2001 p.100)

Bevan and Sternberg, (2012) identified "allostatic load" in informal carers – the total burden on an individual from multiple stressors, and found that high loads led directly to increased risks of ill health for the carer. They identified that carer stress was directly related to the carers experience of caring and not the role of carer itself, suggesting that improvements in carers experiences could help minimise carer burden in the future. Dempsey and Baago, (1998) suggested

that 'latent grief' contributes to caregiver stress and burnout as the carer continually suffers from protracted grieving as the care recipients' health gradually declines (seen particularly in those caring for dementia sufferers). This in effect, results in the gradual but continual renegotiation of the carer identity, protracting the transitional process from previous to carer identity.

As previously demonstrated, the caring role can have a range of impacts on care givers, affecting their social inclusion, ability to perform other roles, and their health and wellbeing. However, informal care can also have effects on relationships with others. The provision of care affects the whole family and its associated burden is felt by all (Dooghe, 1992). The inclusion of the caring role is often an extension of familial duties – an expected addition to current role and its implementation can cause tension in existing relationships (Dean et al., 2014). Leinonen, (2011) suggested that the obligation to care for elderly relatives is encompassed through the strength of historic relationships which are developed over many years. The stress involved in caring can damage these historical familial relationships which can ultimately affect the quality of care provided (Dooghe, 1992). As caring need increases, the historic relationships formed across the whole family may need to change (Leinonen, 2011) which can result in new, previously unimagined sources of tension such as the equitable sharing of carer tasks, the appointment of new responsibilities and the development of altered family rituals – ultimately the renegotiation of familial identities.

> Family ties and the sense of filial obligation are constructed
> and negotiated across the life course and can produce
> tensions in later life relationships.

> Leinonen, (2011 p.309)

The result of caring can be the perceived neglect of certain familial members in favour of others, feelings of frustration and being unappreciated by the care recipient or other family members who do not provide equitable care and even frustrations regarding the financial implications of providing care (Dooghe, 1992). These tensions can be further aggravated due to the actual time spent caring. Glasgow, (2000) stated that due to increased life expectancy, family members occupy their family role for longer, which "*affects the bonds of affection and obligation*" (Glasgow, 2000 p.622). Essentially, the carer role is

prolonged and the resultant change in relationships and tensions within the family are borne for longer.

This section has considered the question "what affects carers?" and has demonstrated that the carer experience is fluid, changing over time and dependent on a variety of factors.

Geographical distance was first considered as an effector for informal care and was demonstrated to have a profound effect on the carer-cared for relationship. Carers were more inclined to provide care if they resided closer to their care recipient (Campbell and Martin-Matthews, 2003), although the relationship between care provision and geographical proximity was not linear (Hamon, 1992). Emotional closeness was also found to be related to geographical closeness but the development of increased remote contact methods have allowed relationships to remain emotionally close even when geographical distance is great (Gilleard and Higgs, 2005). The role of the community in terms of geographical positioning was also considered and found to have an effect on the emotional closeness carer and care recipients occupy. Elderly care recipients were less likely to move homes, unless moving into permanent residential care (Gilleard and Higgs, 2005) as they became more infirm, which may affect the carers ability to provide care. The lessening of emotional bonds between adult children and elderly parents and a greater reliance on spouses for informal care was identified and was shown to allow adult children to occupy greater geographical distances (Gilleard and Higgs, 2005). Rural and urban differences were identified in informal care, including social isolation, loss of services and higher costs in rural areas (ILC, 2013). Relating to geographical differences, academic research concurred that differences in caring in urban and rural populations do exist but struggled to reach definitive conclusions regarding what these differences were and the effect they had on the carer (Creese, 2003, Dwyer and Miller, 1990, Tommis et al., 2007), suggesting that further research is required to understand these differences more clearly.

The motivations that carers experienced to provide care, with particular emphasis on love and obligation were identified as important factors in carer experience and identity. Both motivators were found to be inter-related and both were required (to a greater or lesser extent) to inspire the provision of informal

care (Oudijk et al., 2011). Further motivators to care were also examined, such as the role of reciprocity in caring relationships and between adult children and elderly parents, an obligation to provide care due to societal norms of filial responsibility was identified, but this was based on perceived obligation due to care and financial assistance received in earlier life (Bengtson and Roberts, 1991) and also from continuous reciprocity arrangements such as financial rewards and inter-relational exchanges such as childcare provision, exchanged for informal care (Raschick and Ingersol Dayton, 2004). The potential for future bequests was also identified as a motivating factor to provide care (White-Means and Hong, 2001).

As well as motivations to provide care, extant literature revealed the personal effect that caring has on carers and their wellbeing. Loneliness and isolation were found to be prevalent among carers (Jo Cox Loneliness Commission, 2017) due to the limited time and financial resources available to carers to pursue relationships external to the carer-cared for dyad. Research identified the importance of carer breaks (Carers UK, 2017), which could be supported by technology to assist in improving the wellbeing of carers. Other forms of carer burden were also identified, such as the encumbrance of multiple roles (Stephens and Franks, 1999) and the effect of carer stress on health and wellbeing (Bevans and Sternberg, 2012). Research identified that tensions among wider family members may also increase as a direct result of informal care provision (Leinonen, 2011), potentially increasing carer burden further. All identified research on carer burden sadly confirmed the existence of negative consequences for carers, as a direct result of providing that care.

As demonstrated, many things affect carers, including how, where and why they provide care, the relationships they have with those around them and the resulting stress they feel from providing that care as well as the effect that caring has on their own health and wellbeing. So far this literature review has considered the elderly and infirm population and has identified that issues in informal care provision exist; has identified who carers are in terms of demographical information and relational attachments; and has identified what affects them in their caring role, and how. The extant research has so far failed to consider the caring role from the perspective of the change in self-identity of

the carer, why and how this change occurs and to what degree, and how this change in identity relates to the carer experience, the burden felt etc. The next section considers self-identity in carers – how the carers see themselves and whether self-identity changes occur with the addition of the caring role and also contemplates the inception, development and transformation of family identities involved in caring.

2.4. Identities of caring

So far, this review of literature has highlighted many of the issues related to informal care. This next section considers the carer and 'he care recipient as self-identities which are adopted to a greater or lesser extent by those involved. The roles that possessions, objects and rituals occupy in developing, maintaining or changing identities are also examined.

2.4.1. Carers, care recipients and family

The identity of carer is situated in the tacit, internal acknowledgement of the same self-identity – one can only be a carer; policies and services will only apply; and the role can only be relinquished if the carer identity is accepted and recognised by the care giver themselves. However, O'Connor, (2007) considered the importance of the positioning process of self-identified caregivers and its usefulness. The study consisted of a series of in-depth qualitative interviews with a variety of carers, including men, women, spouses, sons, daughters and other relatives. The study showed that without external influence, family members struggled to see their caring role as more than just an extension of their accepted familial position - thus the label of caregiver was socially and externally constructed and the identity either accepted or rejected. This supported Gooberman-Hill and Ebrahim, (2006) who questioned whether informal care was an appropriate label to apply to the complexities of providing care to a family member. They found that:

> As older people seldom describe their relationships with
> significant others as 'care', it may be more appropriate to
> discuss informal care provision with patients by using the
> language of relationships.

Gooberman-Hill and Ebrahim, (2006 p.261)

O'Connor, (2007) considered this self-positioning to have important positive and negative aspects. Once self-positioned as caregiver, respondents were more likely to source social support and became visible to Public and Voluntary services. However, the positioning of the caregiver also results in other complementary positioning which may not be readily accepted by all involved: *"specifically, it is through the process of constructing a 'caregiver' that a 'care recipient' is simultaneously constructed"* (O'Connor, 2007 p.173). In addition, once the label of caregiver is applied previous identity labels of familial position (daughter, son etc.) begins to wear away: *"carers experience the loss of their identity…and other personal and social identities are reduced as the demands of caring dominates their lives"* (O'Shaughnessy et al., 2010 p.253), raising *"existential issues"* for carers (O'Shaughnessy et al., 2010 p.255). Likewise, the care recipient may feel loss of autonomy and familial position when their label is applied, although behaviourally, little change to the norm has actually occurred – the addition of the carer-care recipient labels of identity alter perception of those involved.

As O'Connor, (2007) suggested, carer identity can only be formed when there is a care recipient to justify that label. This supported Baikie, (2002) who found that the majority of spousal carers self-identified as 'spouse', not 'carer'. However, once accepted, the carer identity or care persona (Broady, 2017) becomes *"central to a carer's understanding of self-identity and role within the familial unit"* Broady, (2017 p.373). The carer persona may be interpreted in a positive manner by the carer and in fact become more important; more personally fulfilling than other self-identifiers, giving rise to the carer 'martyr' – an encompassed identity which revolves around the carer role to the exclusivity of all else, including the needs of the carer themselves (Broady, 2017).

Barnhart and Penaloza, (2013) considered the negotiation of age identity through consumption behaviour and their elderly consumption ensemble, or ECE was defined as *"an elderly consumer and at least one other person who together engage in the consumption activities of that elderly consumer… [and] improvises ways to continue the older person's consumption"* (Barnhart and Penaloza, 2013 p.1134). This research focused on constructing identity through

the consideration of old age and its associated consumption behaviour – who is 'old' and what it means. The research confirmed that *"consumption activities are the means through which older people negotiate their age identity"* (Barnhart and Penaloza, 2013) but suggested that although people are active agents in the production of an identity via consumer behaviour, they do not necessarily do this without the input of others – namely their ECE. Therefore, age identity is formulated in conjunction with others – a *"socially constructed subject position"* (Barnhart and Penaloza, 2013 p.1134). Lee and Collins, (2000) suggested that this may result in conflict between family members and the use of coalitions and tactics which should be of particular importance for marketers as these conflicts (and primarily their resolution) can impact consumption and purchase behaviour (Lee and Collins, 2000). The research demonstrated that old age identity may not be recognised as a self-identity by the elderly person until long after other ECE members have applied the old age identity to them, an idea supported by Mathur and Moschis, (1999 p.78) who found that *"unfortunately the older person's subjective evaluations are not very useful, since the elderly are not always aware of their own frailties, or they do not admit them in an effort to defend their self-concept"*. This somewhat contradicts O'Connor, (2007) who suggested that no carer identity could exist without the acceptance of the associated care recipient identity by all parties. Barnhart and Penaloza, (2013) suggested that the self-identities of carer and cared for can exist without the other, if the individuals do not share their positioning of the other (although they refer to the identities associated with age, not necessarily informal care). Their example is that of a Mother cared for by her daughter. The daughter has positioned her self-identity as that of carer and her Mothers identity as an elderly care recipient. However, the Mother did not feel she needed care, or that care was being provided by her daughter as such an admission would have confirmed that she was "slipping" when she didn't "feel old" (Barnhart and Penaloza, 2013) – the Mother's self-identity did not include that of a care recipient or an elderly person. It is therefore only when the other person in the caring dyad attempts to identify and enforce their own interpretation of the others identity on them that tensions emerge.

The dependence of the carer identity on the existence of a care recipient can become problematic on the death of the care recipient. The self-identity of carer

is lost and a replacement identity can be difficult to attain. For some carers, the death of the care recipient becomes an opportunity to re-establish previous life activities, or to re-engage the identity they suspended when they became a carer (Broady, 2017). However, the majority of carers do not return to a previous identity, but form a third identity, (Broady, 2017; Daly, McCarron, Higgins and McCallion, 2013); the first being before they became a carer, the second during caring and the third on termination of the caring role. Broady, (2017) suggests that transition to this third identity is made easier if carers maintain interests outside of the caring role as not all elements of the second identity would then terminate on the death of the care recipient. Thus, the self-identity of carer must be accepted by all those involved in care and must be temporary – for as long as the care recipient identity also exists. Daly et al., (2013 p.503) argued that carers identify themselves as *"living on the fringes"* of real life; That the carer identity is removed from their original normative expectations (Abma et al., 2012) and so require increased development of social networks to counteract social isolation. Specific carer support groups exist across the UK which may *"facilitate the inter-relatedness, collegiality and belonging so central to place"* (Daly et al., 2013 p.506) which may then assist in the transition to a third identity when caring ceases. However, this research considers a number of identity transitions for carers, but does not identify the process by which they occur.

Movement from an individual residing independently to full time residential care has a number of impacts on the care recipient and Abma et al., (2012) suggested that institutionalisation has a depersonalising effect and stimulates passivity in the care recipient through the individual's inability to contribute, control or change their life and living conditions. This work identified independence as a value in itself in that each individual is morally bound to care for themselves for as long as they are able and emphasised personal responsibility for each individual's own life path (Abma et al., 2012). Thus, the retention of independent living for as long as possible is crucial for many elderly individuals and the reduction in dependence a transitional process. Therefore, informal care from family members may also be crucial to the preservation of independence and identity and the transition towards dependence. Although Abma et al. (2012) concentrated on care recipient identity changes in their

research, any change in care recipient identities affects the corresponding carer identity, as one cannot exist without the other (O'Connor, 2007).

Abma et al., (2012) argued that true autonomy can only be developed through relationships with others – *"relational autonomy"* (Abma et al., 2012 p.28). An example provided by Abma et al., (2012) was a family member reminding the care recipient to take their medication, allowing them to remain living in their own home. The carer acted as a tool to preserve autonomy by reminding the care recipient of a need they had, which, if left unmet, may have jeopardised their autonomy by forcing them to consider residential care. Thus, the informal carer identity is not formed to counteract the autonomy of the care recipient, but to aid it. The authors suggested that autonomy is more than just an individual's ability to make decisions without external influence and involves feelings of self-worth and self-development; *"autonomy is not an individual exercise but an interactive process requiring the help and support of others" (Abma et al., 2012 p.30).* Moore, (2016) confirmed that an individual's sense of agency is the feeling of *"being in the driving seat when it comes to our actions"* (Moore, 2016 p.1) but reported that a sense of agency is consciously constructed by the individual involved – therefore the experiences and facts of agency can be quite different things. This suggests that agency is a subjective concept, contributing to one's 'self' regardless of whether agency is held in reality and can actually be associated with poor health and quality of life (Moore, 2016). Because of this, agency in the carer-cared for dyad is an important consideration when examining caring identities and in particular, the transition of agency as the new caring identity develops.

Once the identity of care recipient is accepted, the identity of care-giver is also borne, and whether this is perceived as a positive or negative change, readily accepted or fought over is dependent on those individuals involved. Complex informal network dynamics and historic relationships between those involved are key considerations as the identities of carer and care recipient are formed, and their development can cause tension in the acceptance of the new carer-cared for identities (Allen et al., 2012). The sharing of expectations throughout these changes may result in a reduction in tension between parties and

improvement of care experienced by the care recipient (Abma et al., 2012) as the caring identities become more defined and accepted.

Development of caring identities can also impact the wider family identity and how they *"do family"* (Barnhart et al., 2014 p.1683). This can result in the renegotiation of the collective family identity.

Family-provided care creates a complex relationship whereby existing dynamics are subject to change. This is particularly apparent when care involves a number of family members, (as already discussed) and research for understanding the implications for identities between family members is currently limited.

> The possibility of conflict regarding caregiving and the roles
> of different family members in providing care suggest that
> family members may have incentives to behave strategically.
>
> Pezzin, Pollak and Schone, (2015 p.970)

Research by Pezzin et al., (2015) examined the filial care relationship in terms of parent-child co-residence and the effects caring had on siblings and level of care provided. The research found that co-residence resulted in loss of privacy and autonomy for both carer and cared for, affecting identities insofar as the change in residential status altered power structures within the family. The level of care provided by other siblings dropped once the elderly parent co-resided with one adult child (Pezzin et al., 2015) potentially because the lead sibling adopted the carer identity to such an extent that the remaining siblings felt extraneous, which may be contentious among family members.

Ho, (2008 p.128) proposed the existence of an inter-relation *between "self-determination and well-being"* and that the 'self' is inter-related with autonomy and agency. Ho, (2008) argued that family involvement in sustaining the autonomy of the individual (in the context of this thesis, the elderly care recipient) promoted the overall agency of the individual because the 'self' is never external to social context, supporting other research claims (Barnhart et al., 2014; Ekstrom, 2004; Epp and Price, 2008; Hiedemann and Stern, 1999) that decision-making is a group phenomenon. This suggests that the preservation of autonomy in the care recipient may actually secure caring identities as static for longer, preventing their transition and allowing family

members to occupy their previous family identity and role for a greater length of time.

> In moral philosophy, the self is often considered the locus of autonomous agency and responsibility…. From Descartes to contemporary theorists, many philosophers consider the self as individualistic, isolated and ahistorical, assuming that the criteria that determine one's moral identity over time are independent of the social context in which they are situated. One of the effects of such a contextual notion of identity in moral philosophy is the refutation of the inherent significance of intimate relationships

> Ho, (2008 p.129)

Mathur and Moschis, (1999 p.77) agreed that consumer researchers have a need to understand the process of care giving and receiving but claimed that studies focused on the carer-cared for dyad are *"virtually non-existent"* and that the needs and wants of this group require further examination to understand their experiences and the dynamic nature of identity in informal care.

The family means different things to different people. There is no such thing as a typical' or nuclear family and Morgan's (2011) 'cornflake family' consisting of Mother, Father and two children no longer holds credence as the typical or ideal structure for the modern family. Common ancestry, the rule of living under the same roof (Ekstrom, 2004; Higgins and Hamilton, 2014) or having blood ties (Higgins and Hamilton, 2014) are no longer appropriate definitions for family. The definition of family is culturally determined and constantly changing (Ekstrom, 2004) and 'family' is a structure mutually defined by membership above all else (Higgins and Hamilton, 2014) and through the family members' own normative expectations (Abma et al., 2012). Families construct 'family' together, both from *"being and doing"*, (Barnhart et al., 2014 p.1681; Cheal, 2002) and meaning within families is constructed by how actors act in certain circumstances and are continuously changing (Ekstrom, 2004). Identities within families that include elderly relatives may change throughout the life cycle (Trees and Dean, 2018) and members develop many different identities through social construct in an effort to deal with different issues in different contexts (Ekstrom, 2004). One of these issues is the provision of informal care – a single carer identity which may exist among multiple identities within the family

construct (Ekstrom, 2004), such as carer, daughter, social planner, manager of family finances etc.

Huff and Cotte, (2016) considered adult children and their elderly parents through the lens of assemblage theory. They conceptualised 'family' as an evolving assemblage of components which was fluid in nature, changing in response to changes in the life-course of its members. The research described the transitions between stages in the family life cycle, with specific emphasis on the latter stages, which were marked by changes in responsibilities and roles for its members – essentially altering the identity of the family by the change in the identities of its members in response to changes in their collective situation. This research focused on the consideration of the family as a *"state of being and a process of doing"* (Huff and Cotte, 2016 p.894) but did not consider how these transitions felt for those involved – whether they were welcomed and what effect they had on the individual self-identities of those involved.

2.4.2. Artefacts, possessions and rituals

The development and transition of family identity is of great significance in understanding informal care within families (Trees and Dean, 2018) and Cheal, (2002) suggested that family identity is constructed through the repeated ritual of family practices- *"repeated activities – routines and rituals… sustain the reality of the family"* (DeVault, 1991 p.54). Rituals strengthen the relationships between family members by providing opportunities for communication and memory-building which is particularly important for women (Meske, Sanders, Meredith and Abbott, 1994).

Finch, (2007) proposed that family activities and rituals confirm the existence of 'family' to both wider society and the family members themselves – that by doing family things (such as experiential consumption, (Higgins and Hamilton, 2014)) they are in fact a family. However, the commencement of informal care can terminate or alter existing family practice and also create new ones. The continual renegotiation of family ritual is crucial during family transitions (James and Curtis, 2010; Trees and Dean, 2018) such as the commencement of informal care. This renegotiation can be a source of tension among the family (Dean et al., 2014; Trees and Dean, 2018) as family members define and

accept new positions within the collective family identity. Family rituals, such as the sharing of a meal, and societal celebrations such as Christmas and Easter are symbolic methods for the sharing of familial identity and can therefore become incorporated into self-identity (Belk, 1988). The ritual and products associated with such celebrations can be viewed as part of a *"hedonic consumption paradigm"* (McKechnie and Tynan, 2008 p.1013) but are context-specific. Therefore, the use of routines, rituals, artefacts, possessions and objects in expressing self are not exclusive to each other, but rather can be used to maintain or extend multiple levels of self – self-identity, family identity, group identity and the like (Belk, 1988; McKechnie and Tynan, 2008).

Phipps and Ozanne, (2017) identified routines as an integral part of making people feel secure, although they are often taken for granted practices that have become adopted into everyday life. Disruption to these routines can lead to existential insecurity, which goes beyond "*discursive consciousness"* and can alter the ontological state of those involved (Phipps and Ozanne, 2017). This can be seen particularly in the relationship between carer and care recipient as a change in ontological state can affect self-perceived levels of empowerment. Changes in the perception of power in caregiving relationships can result in the insecurity becoming more permanent and result in tension between those involved (Phipps and Ozanne, 2017). Therefore, changes in rituals can lead to changes in self-identity.

The renegotiation of family ritual is heavily emphasised by emotional attachment, however emotional attachments can also be applied to possessions and artefacts by both the carer and care recipient.

> Objects are non-human active social entities which accumulate personal value according to the interactions they have been party to.
>
> Epp and Price, (2010 p.821)

Possessions act as both a component and representation of self-identity (Belk, 1988) and our understanding of consumer behaviour is dependent on understanding the importance that individuals inveigh their possessions with (Belk, 1988). Belk's (1988) "*extended self"* included self-interpretation of 'me' but also of 'what is mine' and both together formulate identity. Possessions

themselves can symbolically 'extend self' so that feelings and emotions are heightened in proximity to certain objects (Belk, 1988). This is of particular consequence in the consideration of elderly individuals and carers as former identity markers such as employment, friends and hobbies may fade away, but the extended self can be preserved through the investment of meaning in certain objects (Belk, 1988). Not only can objects be used for identity in the present, objects can also be used to preserve past experiences, memories, emotions and former identity.

> The possessions in our extended self also give us a personal archive or museum that allows us to reflect on our histories and how we have changed. Through heirlooms, the family is able to build a similar archive and allow individual family members to gain a sense of permanence and place in the world that extends beyond their own lives and accomplishments.
>
> Belk, (1988 p.159)

Possessions can also be used to reflect different aspects of self-identity, for example an expensive car can be used to reflect a desired social identity which may be somewhat removed from the reality of true self (Belk, 1988), or a care recipient may use a motorised scooter for public appearances, despite being fully mobile in the home – effectively modifying portrayed identity to reflect a different perceived identity for any number of reasons. This can also be seen in the symbolism imbued in objects given as gifts – the act of both giving and receiving the gift can be used as a reflection on the strength of the relationship between the two and the consumer behaviour involved seen as a labour of love (Fischer and Arnold, 1990).

Mortelmans and Sinardet, (2004) described gift-giving as a principle seated deep in modern societal and cultural organisation which can reveal *"important cultural mechanisms of intersubjective relations"* (Mortelmans and Sinardet, 2004 p.177). Furthermore, the choice of gift (in particular giving gifts of money or vouchers) can indicate a lack of knowledge of the personalities and therefore likes and dislikes of the receiver, suggesting an explicit emotional distance between the two (Mortelmans and Sinardet, 2004). However, Wong, Hogg and Vanharanta, (2012) argued that gifts that are given become extended possessions and therefore part of the extended self (Belk, 1988) of the giver

and remain so, even after the gift has effectively changed hands from the giver to the receiver:

> The extended possession hence provides informants with an anchoring point to increase the relative stability of their relationship with others, thereby countering the labile nature of ever-changing identity.
>
> Wong et al., (2012 p.936)

McCracken, (1987) considered the person-object perspective in research involving the elderly and their consumer behaviour. It was found that objects are often used as an aide memoire in the lives of the elderly – a repository for previous experiences, feelings and/or relationships. In this way, objects are imbued with meaning which is exclusive to that individual. However, Lovatt, (2018) suggested that research identifying objects used as repositories of identity through symbolic imbuing with emotion and meaning are actually misunderstanding the nature of identity perception and that this can only be the case when these objects maintain their meaning through their continued use in everyday life.

McCracken, (1987) proposed that the meaning attached to objects can be deliberately manipulated to increase an individuals' awareness to a certain concept, evoke a certain response or even to alter the self-perception of the individual. These covert uses of specific objects can be especially useful in intergenerational communications and are not necessarily malevolent in nature (McCracken, 1987) but can *"deliver their messages without drawing the full attention of the recipient"* (McCracken, 1987 p.211). Belk, (1988 p.150) agrees that this is particularly true for gifts given to others, which contain an irrevocable link to the givers and can be used as a *"special form of control"*. The use of objects in the maintenance or change of family identities is therefore an important consideration in familial informal care, as well as providing a tool for carers to elicit certain behaviours. This is because certain possessions and rituals may hold symbolic meanings which are integral to the identity of the family as a whole. Furthermore, everyday consumption practices and rituals often involve the carer and so become part of the constructed family (Barnhart et al., 2014)

The older generation may view the replacement of objects with suspicion and deep consideration because replacing them inevitably means displacing the existing one – the one often imbued with personal meaning (McCracken, 1987). Therefore, an object, regardless of its' attractiveness or actual utility may increase in value to an elderly individual (McCracken, 1987). Consumer research has considered the choice of objects and the personal meaning awarded to them and surmised that the addition of personal meaning often considerably outweighs the object's *"commodity status"* (Epp and Price, 2010 p.820). Objects can therefore inveigh identity to actors, but this may not necessarily be in the desired way or for the desired amount of time:

> When families make seemingly mundane choices about object uses, spatial arrangements and identity practices, they set the stage for network forces to converge in ways that both empower and constrain the focal object's agency and shape its biography… these network transformations do not always unfold as envisioned.
>
> Epp and Price, (2010 p.834)

The changes in normative expectations (Abma et al., 2012) within a family can often bring about the formation of new identities and previously precious objects can lose their inherent meaning, or that meaning can change (Epp and Price, 2010), because an object's inherent value might lay in the personal biography attached to it (Epp and Price, 2010). Any change to this biography or the practices and rituals that surround it can alter the emotional value of the object.

The consideration of rituals and objects is crucial to understanding changes in identity during family transitions, such as the commencement of informal care provided by family members. However, there is little research that considers the use of rituals and objects as tools for identity transitions specifically in informal caring.

This section has confirmed that the identity of carer and cared for is transient in nature and a construct of an individual's normative expectations (Abma et al., 2012). The identity of carer is self-identified (O'Connor, 2007) and to exist there may also be a complementary care recipient identity. The informal care relationship between care recipient and carer(s) develops from complex network dynamics which can result in tensions between carer, care recipient

and the wider family (Allen et al., 2012; Dean et al., 2014). Family identities are re-designed to encompass carer and cared for status (Ekstrom, 2004) which can also lead to tensions between wider family members. The preservation or re-negotiation of family identity is based on emotional attachments to people, objects and rituals, all of which can serve to maintain or change both individual and family identity (Trees and Dean, 2018). Objects and rituals can be used as tools to renegotiate identities but can also be manipulated to evoke certain responses (McCracken, 1987) due to their integral role in the identification of 'family' (Barnhart et al., 2014). However, manipulation of objects and rituals may not always elicit the response either expected or desired (Epp and Price, 2010). To date, the topic of transitions in self-identities in care relationships and the role that objects, possessions and rituals have remains largely unexplored.

2.5. Summary and justification for the research

This literature review commenced with a broad consideration of elderly care and explained that it is in fact a 'big deal' – the UK population is growing increasingly old and infirm and requires more care than formal care can currently provide.

Informal carers are primarily family members and often adult children or spouses of the person requiring care and the number of informal carers in the UK is predicted to hit 9 million by 2037 (Carers UK, 2017). However, changing demographics (falling birth rates, increasing divorce rates) have resulted in the provision of informal carers actually contributing to the growing problem. This confirmed the basis for this research study and the highlighted the importance of continuing research in this area.

Narrowing the focus, the literature review then considered carers as a group – who they are and what they are like, from gender and familial roles to social differences. The research has identified that the majority of carers are either adult children or spouses (Government Office for Science, 2015).

Informal carers were found to be generally female (Finley, 1989; Hiedemann and Stern, 1999; Laditka and Laditka, 2000) and research suggested that women tend to live closer to their parents than men, making it easier for them to provide care (Horowitz, 1985). Female carers were also found to be more likely to manage multiple demands on their time, such as employment and other family responsibilities (Barnes et al., 1995) and so utilise leisure time to provide informal care (Del Rio-Lozano et al., 2013).

The review then concentrated on carers as individuals and what they are affected by, including their physical location, their reasons for providing informal care and the effects that caring has on them.

The propensity for a carer to provide care is motivated by many factors, including love, affection, duty and obligation. A pre-requisite level of affection to inspire care exists (Engster, 2005; Leira, 1994) but moreover, research suggested that the greatest motivators to provide care are senses of moral duty and familial obligation (Oudijk et al., 2011; Daly, 2002) and the greater the perceived obligation, the greater the amount of care given and the emotionally

closer the relationship (Cicirelli, 2000; Engster, 2005; Stuifbergen et al., 2008; White-Means and Hong, 2001).

The effects of caring on the carer have been subject to a great deal of research in recent years and in particular, the effects of loneliness and social isolation (Jo Cox Loneliness Commission, 2017). Both result from lack of time and energy, lack of financial resource, loss of friends and acquaintances and the inability of the carer to leave their carer posts for an extended amount of time, which increases in difficulty with the passage of time (Carers UK, 2017). This literature review clearly demonstrated that providing informal care can have a detrimental effect on the carer (Bevans and Sternberg, 2012). Caregiver stress is common due to the dynamic nature of the role and the multiple demands placed on carers (Bevans and Sternberg, 2012). The burden of multiple roles affects the quantity and quality of care provided to care recipients (Stephens and Franks, 1999) but also affects the wellbeing of the carer and anxiety, depression and insomnia were found to be symptoms of carer burden (Bevans and Sternberg, 2012). Carer burden was also found to affect carers' relationships with others and can result in damage to relationships among the wider family unit (Dooghe, 1992; Leinonen, 2011). Tensions may emerge as new caring responsibilities are assigned, family rituals are altered, financial changes are worked through and self-identities change (Dean et al., 2014; Leinonen, 2011).

Narrowing the focus further, the review then examined the identities of caring. The carer and care recipient identities were recognised as being mutually inclusive and their acceptance was found also to affect the wider family. Objects, possessions and rituals were recognised as potential conduits for the development or acceptance of caring identities, which could be used in a number of ways. The acceptance of the carer identity was found to have both positive and negative consequences in that carers may become more likely to seek assistance from others once the carer identity is accepted, but this acceptance may also strip away old relational identities such as daughter or husband and alter the fabric of the relationship between the carer and cared for forever (O'Connor, 2007). The literature therefore suggests that the transition between old and carer identity may occur by degrees and require the input of others to be successful (Daly et al., 2013).

Complex informal network dynamics occur in families as one or more members' transition to the carer identity (Allen et al., 2012). These changes can result in tensions among the wider family as new roles and responsibilities develop in areas of family life not previously considered (Dean et al., 2014) which may ultimately change the way that that the family does family (Barnhart et al., 2014). The development and transition of individual and family identities may be constructed through the repetition of family practices or rituals (Cheal, 2002) and the adoption of caring identities may provide a catalyst for the renegotiation of those family rituals (Trees and Dean, 2018) which can also be a source of tension amongst family members (Dean et al., 2014). Family rituals are often emotive and may use objects and possessions to accumulate personal (and emotional) value (Epp and Price, 2010).

A gap in the knowledge base exists in considering the transition of identities after the inception of informal caring or after changes in circumstances in care relationships. Research has yet to consider how carers feel about their self-identity as they transition between their former identity and the caring identity they now occupy; how former identities are lost or changed due to their caring involvement; what motivates individuals to desire a change in self-identity and how they actually go about eliciting this change. The justification for this research is that in understanding the transition of carer identities, the needs and wants of carers may also be better understood. This in turn may assist in providing solutions to the problems carers face in their every-day lives – essentially assisting carers to have better experiences in their caring role.

2.6. Aim, Objectives and Research Questions

The aim of this thesis is to understand how individuals transition from their previous identity to that of an informal carer, addressing the gap in current knowledge previously identified in chapter 2. This gap will be addressed by this thesis by the completion of the following research objectives:

1) To understand the impact of distance on informal care identity and its relationship with others
2) To understand the transitional process associated with self-identity when informal care provision commences or changes.

2.6.1. Identity as a conceptual lens

Marketing research (specifically regarding consumer behaviour) into self-identity has been *"fragmented, incoherent and highly diffuse"* (Reed, 2002), with little or no consideration of the effect that caring has on identity transitions and vice versa. Attempts to conduct research under the construct of 'self' have also been problematic (Reed, 2002) and:

> Any paradigm that conceptualizes the self-concept must begin by defining it, because the working definition of the self-concept impacts the dimensionality of the construct…[and] specifies the nature of a potential theory
>
> Reed, (2002 p.236)

The concept of self-identity is widely assumed to be unique to each individual and is based on who we are, where we belong and how we fit in (Oyserman, 2001)

> In its widest possible sense… a man's self is the sum total of all that he can call his, not only his body and his psychic powers, but his clothes and his house, his wife and children, his ancestors and friends, his reputation and works.
>
> James, (1890/1950 p.291) cited in Oyserman, (2001 p.499)

However, Hogg and Michell, (1996) suggest that 'self' is made up of a number of macro and micro levels of identity. Shankar, Elliott and Fitchett, (2009) proposed that the concept of identity is changing – from being a fixed construct

of social position to a dynamic construct which can be assembled, changed and influenced by a variety of other aspects:

> Identity is no longer conceptualized as a 'thing'; rather it is considered a project. A process and a practice which has to be worked on – or reflexively monitored, organised and managed.
>
> Shankar et al., (2009 p.76)

The conceptualisation of 'self' has been interpreted in a number of ways. Researchers may choose to view a single identity with a number of roles or multiple identities which may be static or dynamic etc. Al-Abdin, Dean and Nicholson, (2016) described individuals with a number of 'selfs' – social, domestic and extended which are shaped by both major and minor events in a person's life. This notion supported both Ahuvia, (2005) and Belk, (2014). Ahuvia, (2005) suggested that a 'self' can be made up of a number of different identities and questioned Belk's (1988) concept of a core and an extended self because the existence of a core self suggests the existence of a true or real self that individuals must endeavour to discover. Rather, Ahuvia, (2005) proposed that the self is transient in nature, responding to changes over time:

> We should acknowledge that selfness is a continuous variable with a grey area between possessions that are or are not part of a consumer identity.
>
> Ahuvia, (2005 p.180)

Kleine, Kleine and Kernan, (1993) supported Ahuvia's (2005) suggestion that multiple identities form the 'self', but also extended this to suggest that all identities are not equal in value to the individual and that this may affect consumption behaviours:

> We are attracted to products that are consistent with, and that enable the enactment of, the various social identities which make up our sense of self; the more important an identity to us, the more attractive its associated products.
>
> Kleine et al., (1993 p.209)

Importantly, Kleine et al., (1993) also make the distinction between a self-identity and identity roles:

> People's activities and enabling possessions are organized around their social identities – the multifaceted labels by which their Me is recognized by themselves and members of society… Social identities are derived from social roles, but they are not the same as roles. Roles are consensual prescriptions, behaviors expected of those occupying a particular position in society, and in that sense they partition a society. Identities in contrast, partition a person.

> Kleine et al., (1993 p.211)

Belk, (2014) reviewed alternative formations to the extended self and confirmed they acted as *"an enriched and enhanced set of perspectives for construing the relationship between people and things"* (Belk, 2014 p.253). The alternative formulations considered included *"The expanded self"* – essentially viewing other people as part of 'self'; *"The extended mind"*, which allowed the inclusion of technological advances into our concept of self (such as computers and mobiles phone); *"The multiple and narrative or dialogic self"*, which confirmed the existence of multiple identities and *"The actor network theory"* which recognised that multiple objects and multiple people both work together as *"actants"* in a network to formulate behaviours. Regardless of the formation pertaining to the concept of 'self', Belk, (1990b) suggested that objects and possessions have a direct impact on identity:

> The self is spatially enlarged by such extensions in that our possessions make us bigger people. However… besides being defined by our immediate circumstances we are defined by our pasts and our futures.

> Belk, (1990b p.669)

Transition of identity is a social act which requires recognition from those around us to validate the new identity (Shankar et al., 2009) however, this recognition by others (or lack of recognition) can also become a source of discontent. Our identities are socially constructed to provide *"archetypical identities"* (Shankar et al., 2009 p.80) or role models of identity to demonstrate who we are and how we behave which remain theoretical until put into practice by the individuals around us. As these archetypical identities are reproduced over generations, the characteristics of those identities become deeper ingrained, supported by our society and increasingly static (Shankar et al., 2009). Therefore the transition of identity can cause tensions because the

desired or changed identity may not conform to the expectations of our personal society – the new identity is not the one assigned by others (Shankar et al., 2009).

In periods of dramatic change (such as the inception of care) changes to the image of self can be extreme and occur quickly (Al-Abdin et al., 2016). Noble and Walker, (1997) claimed that identity transition takes place through three distinct phases. Firstly, *"separation"* whereby an individual detaches from their previous identity and roles; secondly *"liminality"* whereby individuals exist between identities, somewhere between the relinquishment of their previous identity and the development of a new identity: *"Liminality is evidenced by solitude, alienation from social existence and withdrawal from present social structure"* (Noble and Walker, 1997 p.31). Thirdly, *"aggregation"* whereby a new identity and its' associated roles are identified and accepted. Prolonged existence in the liminal period may have severe negative emotional consequences for the individual involved (Noble and Walker, 1997) and result in *"profound and disruptive effects on our innermost self-perceptions"* (Noble and Walker, 1997 p.32) by increasing the gap between our actual identity and our ideal or desired identity. Noble and Walker's (1997 p.32) notion of liminal transition reflects that

> A change in a significant life role marked by a transitional or liminal period during which a) personal identities are suspended, producing significant psychological consequences and b) symbolic consumption may be used to facilitate the transition to the new role.
>
> Noble and Walker, (1997 p.32)

Al-Abdin et al. (2016) suggested that there are three parts within the liminal transition stage – "*history, happening and hopes"* (Al-Abdin et al., 2016 p.55) which produces a transitional self that is liminal in itself and in a constant state of flux.

> Within a period of transitional liminality, the extended self appears to have its own notions of what is sacred and what is profane. It is the two dichotomies that assist in shaping the value of the domestic and the social self. In order to produce an ideal self, the transitional self is in constant transitional liminality and is expressed through rituals, symbols and artefacts.

Al-Abdin et al., (2016 p.52)

In addressing self-identity tensions, Ahuvia, (2005) introduced the idea of three methods for reconciling self-identity crises. Firstly, "*demarcating*" whereby one identity is rejected in favour of another, secondly, *"compromising"* whereby an identity is formed part way between two alternative identities, and thirdly*, "synthesizing"* whereby aspects of each alternative identity are taken out to formulate a new third identity (Ahuvia, 2005 p.181).

Supporting Ahuvia's (2005) idea of synthesization, Rindfleish, (2005 p.345) introduced the concept of a *"spiritual supermarket"* whereby individuals can pick and choose aspects of religion and other belief systems to best suit their own purpose in the guise of self-development and identity transition. An example of this is the sanctity of wedding vows, believed and promised at the time of marriage, but later altered, forgotten or replaced to better suit the individuals changing circumstances and identity.

> The rise of individualism has made it possible to define the sacred as that which brings secular ecstasy to the individual and happiness becomes intrinsically implicated with the fulfilment of the self.
>
> Rindfleish, (2005 p.345)

Thus, as a person's life evolves, there is an ever-pressing need for the continual re-invention of self-identity (Rindfleish, 2005).

In considering future identity however, Belk, (1990b) highlighted the importance of considering the past. Belk, (1990b) argued that a sense of past is of particular importance during times of transition, stress and identity tension when futures are uncertain, and that possessions provide a sense of support as well as a *"stimuli for future reflections, communication and consolidation of self"* (Belk, 1990b p.670). Possessions therefore lend a sense of stability to an unstable period.

Artefacts and possessions are objects that assist in the definition of extended self. They assist in the development, transition and endurance of an individual's place in society (Al-Abdin et al., 2016).

> Images of self are related to artifacts of consumption, rituals and symbols and…consumer values are navigated through this difficult landscape.

> Al-Abdin et al., (2016 p.45)

Chernev, Hamilton and Gal, (2011) showed that self-expression is a need felt by all individuals, but that this can be expressed through consumption practices in a variety of ways. The greater the number of ways available to express 'self' the less importance any one method or expression may have. This potentially explains why certain possessions or consumption activities are perceived to hold more value than others.

> One of the significant marketing changes in the past decade involves the dramatic increase in the variety of ways in which consumers can express their identities.

> Chernev et al., (2011 p.66)

This concept is supported by Al-Abdin et al., (2016) who suggested that consumption practices define how we wish to portray ourselves to wider society and also our own local community (Al-Abdin et al., 2016).

Possessions are of extreme importance during liminal periods, for example, possessions can act as conduits for transporting the 'self' during a geographical relocation (Noble and Walker, 1997). Even possessions which are utilitarian in nature, such as televisions and radios can hold significant emotional value as vessels of symbolic meaning during the liminal phase and can be used in two ways (Noble and Walker, 1997). Firstly, they may act as replacements for absent social and personal relationships that are no longer part of the extended self and secondly, may act as facilitators for the development of a new identity (upon which, they may then lose their emotional value and symbolism (Noble and Walker, 1997).

Shankar et al., (2009) agreed that consumption can be an empowerment tool to assist in the creation of an individual's ideal self-identity and that possessions can become a *"personal archive"* for the recollection of memories (Shankar et al., 2009 p.78). Personal consideration of these possessions then becomes the *"cultural construction of subjectivity"* in that tensions may emerge between the

individual's current or desired self-identity and the social constructs enforcing stasis or an undesired change in self-identity (Shankar et al., 2009 p.78).

Conversely, Ahuvia, (2005) claimed that love and happiness are intrinsically linked to objects of emotional attachment and that these objects *"serve as indexical mementos of key events or relationships in the life narrative, help resolve identity conflicts and tend to be tightly embedded in a rich symbolic network of associations."* (Ahuvia, 2005 p.179)

For this research, identity is defined as a transient construct consisting of a narrative of identity – the 'who am I?' descriptor, a narrative of values – the 'what do I value?' descriptor and a narrative of relations – the 'who do I connect with?' descriptor (Abma et al., 2012). Together, these narratives form an individual's normative expectation (Abma et al., 2012) – a self-identity constructed according to these personal narratives. Oyserman, (2001 p.499) confirmed that *"being human means being conscious of having a self and the nature of the self is central to what it means to be human".* The 'self' is the repository for self-knowledge and contains the tools we use to make sense of our experiences, how we construct and defend what we know, how we organise our memories and experiences and how we end up feeling about things (Oyserman, 2001). This research supports the idea of multiple identities which may co-exist (Ahuvia, 2005, Al-Abdin et al., 2016) and consist of multiple roles (Kleine et al., 1993).

Therefore, based on the aims and objectives specified through the conceptual lens of self- identity, the research questions to be answered by this thesis are:

1. How does the caring role affect carers' perception of identity?
2. How do carers feel about the changes to their self-identity?
3. How does distance affect the caring role?
4. What mechanisms are available to help carer self-identity transition?

Chapter 3. Method and Methodology

3.1. Methodology

The metatheory applied to a particular area of study is an important deliberation in research design and has largely been dictated by the aims and objectives already identified, as well as the ontological and epistemological position of the researcher. The philosophy of the researcher in terms of the framework for understanding the construction of reality and the framework for which that knowledge is justified are important considerations and reflect the ethical approach to the research design.

> [Researchers] approach their subject via explicit or implicit assumptions about the nature of the social world and the way in which it can be investigated.
>
> Burrell and Morgan, (1979 p.1)

Therefore, the next sections consider the ontology and epistemology which serve to anchor the research within a specific theoretical paradigm.

3.1.1. Ontological and epistemological approach

Morgan and Smircich (cited in Cunliffe, 2011) suggested that researchers are required to illustrate their assumptions about the nature of social reality and 'what it means to be human' in their research. The ontological approach provides the philosophical understanding of existence in which the research is embedded, essentially what there is to know; *"Ontology is the starting point of all research, after which one's epistemological and methodological positions logically follow"* (Grix, 2002 p.177).

Morgan and Smircich (cited in Cunliffe, 2011) also confirmed that researchers need to define their perspective of knowledge; what its purpose and nature is. The epistemological standpoint considers the theory and nature of knowledge, in essence, what and how we know about it (Grix, 2002). Knowledge regarding the assumptions that underpin the research from a metaphysical standpoint are important and assist the reader in understanding the interrelationships of the key components of the research, help to avoid confusion and define the researcher's standpoint (Grix, 2002).

The combination of ontological and epistemological approaches of the researcher directs the nature, purpose and flow of the research project at every stage, including the method for data collection and its analysis:

> Our metatheoretical assumptions have very practical consequences for the way we do research in terms of our topic, focus of study, what we see as "data," how we collect and analyse that data, how we theorize, and how we write up our research accounts.
>
> Cunliffe, (2011 p.651)

This research focuses on the life experiences of the participants; what affect caring has on identities and how they may change. The focus is therefore, on interpretation by individuals, not about widely accepted facts. Creswell, (1998 p.9) states *"qualitative inquiry represents a legitimate mode of social and human science exploration without apology or comparisons to quantitative research".* The emphasis is on dialogue and debate between the research participants and the researcher and therefore interrogates the lived experience of the participants, individual to each. For this reason, a positivist approach to the research has been rejected by the researcher and an intersubjective ontological

approach taken. In this ontological approach reality is socially constructed; interpreted by individuals through their own experiences and 'fact' is a personal projection of that interpretation.

An interpretive approach has been taken which formulates perceptions, understandings and meanings as the primary data source (Mason, 2002). Reality is determined by the individual in it, not by objective, external factors (Easterby-Smith, Thorpe and Jackson, 2012). Therefore, focus will be directed on the way in which people make sense of their experiences (Easterby-Smith et al., 2012) because "*the social world is humanly produced in ongoing activity and routines*" (Cunliffe, 2008 p.125) and therefore 'facts' are products of social construction.

Within the intersubjective ontology there are a number of alternative approaches that were considered for the purposes of this research. Distinctions between qualitative inquiry approaches enable the development of more rigorous and sophisticated studies and provide researcher with clarity about the aim of their research (Creswell, 1998).

Ethnomethodology was considered as a theoretical approach and is a method which focuses on ways in which individuals make sense of everyday life. However, ethnomethodology deals in description only, rather than explanation or evaluation (Sharrock and Anderson, 1986). The study of everyday life and the methods employed to understand it are integral parts of this research. Therefore, it is essential that a research method which allowed the attachment of meaning to observations in every-day life was used, which also still allowed for description. Thus, an approach which focused on interpreted meaning of experience in dialogue and relationship was more suited to this research. Social Constructionism is an empathic epistemology centred on the perspective of the research participants or actors in understanding the social world - *"a transcendental science of pure consciousness"* (Moran and Mooney, 2002 p.60). However, as previously stated this research was based on both a description and understanding of the lived experience and so a phenomenological approach was utilised. Phenomenology as the *"movement inaugurated by Edmund Husserl 1859-1938" (*Moran, 2000 p.1) considers the topic of interest or phenomenon and attempts to get to the truth of the matter to

identify and understand the phenomenon being studied (Moran, 2000). Phenomenology considers reflexivity – how and why individuals behave in certain ways (Kafle, 2013), explores *"the structure of consciousness in human experiences"* (Creswell, 1998 p.51) and is embedded in the narrative performances of ordinary interactions. A phenomenological approach accepts that the knowledge gained is temporal – existing only in that moment, embodied, dynamic and on- going but also accepts that the pursuit or possession of knowledge can never be separated from the individual. Phenomenology emphasises *"the intentionality of consciousness where experiences contain both the outward appearance and inward consciousness based on memory, image and meaning"* (Creswell, 1998 p.52). Cunliffe, (2008) suggests that reality is formulated through the lived experience of the everyman. This experience is therefore individualistic, internalised and a product of social interaction "*Social realities and identities are created and maintained in conversations with others"* (Cunliffe, 2008 p.125).

The use of a phenomenological approach to this research supports the conceptual lens of self-identity previously discussed, as the 'self' incorporates what we think we know, how we know it, how we make sense of it and how we feel about it; that the 'self' is in fact *"a social product that develops through relationships with others"* Oyserman, (2001 p.506). The concept of 'self' is formulated and dependent on the individual's phenomenological field (Reed, 2002)

> *The fundamental thesis of the phenomenological approach is that no one can ever observe a real self directly. The sense of self can only be inferred, but more importantly, must be viewed through someone's perception. Therein lies the conceptual contribution of the phenomenological view of the self-concept and its explicit recognition of the difference between two distinct frames of reference: The objective observer and the thinking, perceiving, and behaving individual.*

> Reed, (2002 p.244)

The dialogue of experiences and understandings between the research participants and the researcher were the source of data to expand knowledge and understanding. Each collective relationship within the family group was the truth to that specific group, seen through the prism of their specific experience,

understanding and interpretation; *"The perceptual 'something' is always in the middle of something else, it always forms part of a 'field'* (Merleau-Ponty, 2002 p.4).

The nature of phenomenological research is ultimately the researcher's interpretation of the participant's experience which has serious ethical factors:

> To renarrate a life unasked … robs the Other of a piece of his or her freedom…I don't think we can underestimate the projected, imagined powers our apparent authority, which rests on our access to print, invokes.
>
> Josselson, (1996 p.67)

However, the focus for this research was the collective experiences, perspectives and interpretations of the participants and the researcher, how the actions, judgements and power within the research relationship were intersubjective, embodied and dialogic - that is, influenced and shaped by the collective 'we' to produce a collective understanding (Cunliffe, 2003). Cunliffe, (2003) terms this approach as "second order dialogic", that is, an intersubjective, adaptable process which is subject to the negotiated interpretations by all participants, including the researcher – the researcher being active and reflexive in data production (Mason, 2002).

3.2. Method

The research design was intersubjective and abductive in nature and aimed to develop new theory from some aspects of the data, and use existing theory to explain other aspects of the data. The research focused on the epistemology of discovery rather than validation (Cunliffe, 2017) and was based on a snapshot in time of a micro-population, had a deep focus and possessed a prospective outlook for conclusions by looking to explain things and not predict things in the future.

3.2.1. Interviews

The data collection method utilised in this research was qualitative interviews – a *"construction site of knowledge"* (Kvale, 1996 p.42) and based on the conduction of a *"conversation with a purpose"* (Mason, 2002 p.67) whereby knowledge is constructed rather than excavated (Mason, 2002) and *"social realities and identities are created and maintained in conversation with others"* (Cunliffe, 2008 p.125)

This method supports the phenomenological approach chosen by the author and can be explained by the following introduction by Spradley, (1979) in Kvale, (1996 p.125):

> I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and help me understand?

> Spradley, (1979)

Kvale, (1996) suggests that consideration be given to 5 post-modern constructionist features; Firstly, the conversation – dialogue between two individuals regarding a subject of mutual interest; Secondly, the narrative – the story-telling aspect of communication; Thirdly, the language – not what, but how aspects are described; Fourthly, the context – the interpersonal context of the interview, which is not automatically transferable and fifthly, the inter-relationality – the *"interchange of views between two persons conversing about a common theme"* (Kvale, 1996). The interview process must record the

essence of the conversation – Husserl, (1913) cited by Moran, (2000 p.1) describes quality in phenomenological approach as:

> This phenomenology must bring to pure expression, must describe in terms of their essential concepts and their governing formulae of essence, the essences which directly make themselves known in intuition, and the connections which have their roots purely in such essences.
>
> Husserl, (1913) cited by Moran, (2000 p.1)

Adopting qualitative interviewing as a research method confirms the epistemological position of the research which:

> Allows that a legitimate or meaningful way to generate data on these ontological properties is to talk interactively with people, to ask them questions, to listen to them, to gain access to their accounts and articulations.
>
> Mason, (2002 p.63/64)

However, the interview process must be reflexive and consider the impact that the researcher has on the research process (Cunliffe, 2017). As an interview is completed, the researcher must acknowledge that *"you cannot separate the interview from the social interaction in which it was produced (because you cannot separate 'facts' from contexts)"* (Mason, 2002 p.65). This intersubjective approach is supported by Cunliffe, (2008) who asserts that meaning is created with others, with no one person directing the interpretation of reality, is experiential, relational and interactive on a micro-level and cannot be separated from others as *"we are always in relation to others whether they are present or not"* (Cunliffe, 2008 p.128) or as Merleau Ponty, (1964) (cited in Cunliffe, 2008 p.129) explains:

> When I speak or understand, I experience that presence of others in myself or of myself in others…To the extent that what I say has meaning, I am a different 'other' for myself when I am speaking; and to the extent that I understand, I no longer know who is speaking and who is listening.
>
> Merleau-Ponty, 1964

3.2.2. Rural and Urban study areas

The research was originally concerned with understanding differences in carer experiences in rural and urban regions. To that end, two distinct geographical areas – one rural and one urban were used as the basis for participant recruitment. Because of the researcher's professional relationships in the area, the two locations used were the city of Kingston Upon Hull for the urban area and East Yorkshire for the rural area.

The Office for National Statistics, (2013) gives an average population density of 413 people per square kilometre in England. In Hull the average population density is 3,605 people per square kilometre – almost 9 times the national average. The East Riding of Yorkshire has a population density of 140 people per square kilometre – 3 times less than the national average and 26 times less than Hull. This definition was deemed sufficient to define Hull as an urban area and East Yorkshire as a rural area in the context of English residential populations for the purposes of this research. To that end, participants were allocated to a study group based on the geographical location of the care recipient – either themselves (if they were the care recipient), or the person they were providing care to. The care recipient had to reside in one of the study areas although the carer themselves could live in any location.

3.2.3. Inclusion Criteria, Recruitment and Sampling method

To provide clarity with regards to the status of potential participants, the following inclusion criteria were used for recruitment purposes:

1. Care recipient must be 65 years old or over
2. Care recipient must live in the study area
3. Care recipient must receive care from at least one informal source
4. Participants must have capacity to provide informed consent

Sampling and the selection of participants allows the researcher to identify, choose and gain access to their potential data sources (Mason, 2002) and is *"as likely to be as strategic as it is practical"* (Mason, 2002 p.121). Judgemental sampling strategy was initially utilised, then continued in conjunction with

snowball sampling, based on the participant's ability to contribute to the evolving theory (Creswell, 1998). New interview subjects were sought until theoretical saturation occurred (Kvale, 1996). Participants were deemed appropriate for the purposes of the research (by the researcher) according to their ability to contribute to the developing theoretical framework, provided that they met the inclusion criteria and the interviews were conducted over the course of one year.

Some participants were recruited to the research through attendance at the East Yorkshire Carer's Support Group. At this meeting the researcher was invited to attend the East Yorkshire Carer's Advisory Group (CAG). This was a monthly meeting whereby a representative from the local Carer's groups, representatives from health, social care and voluntary services all met to discuss more strategic aspects of caring, with a view to implementing real change through the revision of local policies for carers. At this meeting it was revealed that the group had recently advertised in the local quarterly council magazine 'Your East Riding' (Winter, 2016, edition 24), which is distributed to every household in the East Riding of Yorkshire. The article asked for carers to write in with tales of their caring experience. The Chair of the CAG requested the involvement of the researcher in the production of a report based on the responses to this request for data. It was agreed that the resulting data could also be used for the author's own research into caring, and consent from those individuals whom had submitted a statement was sought and secured prior to its inclusion in this body of work.

The result was a further data source of twelve statements from carers in the East Riding of Yorkshire (given study group code 'S') which were then transcribed into NVivo and treated in the same manner as the transcribed interviews. The majority of these statements were provided anonymously, but often contained demographic information, such as place of residence, age of participant etc. which were redacted from the finished thesis.

3.2.4. The Elderly Consumption Ensemble

The research conducted involved the examination of the caring relationship between elderly individuals (over 65 years of age) and the people who provided

care to that individual. Participants included the care recipient themselves, members of the family such as spouses, sons and daughters etc. and other individuals who provided care, such as neighbours and friends. The exact composition of the group providing care varied from participant to participant. For the purposes of this research, the term identified in the work of Barnhart and Penaloza, (2013), "Elderly Consumption Ensemble" or "ECE" has been used to describe the group of individuals providing some level of care to the elderly individual. Although the research was focused on the experience of carers, a limited number of care recipients were also included because the experiences of carer and cared-for are inextricably linked and care recipients have unique perspectives of the caring role.

3.2.5. Ethical Considerations

Hopkins, (2007) stressed the importance of considering the personality and physical attributes of the researcher in conducting research as they are read and interpreted continuously throughout data collection by the participant. Consideration of the potential biases of participants with regards to aspects such as gender, sexual orientation, accent, ethnic origin, class and educational attainment etc. must also be considered to ensure transparency in research design and data interpretation and to acknowledge the potential for preconditioned responses in research (Sultana, 2007). The development of rapport and the identification of shared qualities, characteristics and experiences to develop it, cannot be left without comment in research completion (Hopkins, 2007) because the perceived basis of an 'affinity' (Sultana, 2007) between the researcher and their subject is instrumental in the revelation of personal information which the researcher then treats as data, potentially resulting in unequal power relations between researcher and researched (Sultana, 2007). In fact, Tang, (2002) considers both researcher and researched locked in a continual power relationship based on perceptions of cultural, social and personal differences. Citing Oakley, (1981), Tang, (2002) suggests that quality interviews can only be achieved when power relations are equal, and that the identification of some level of shared identity and therefore shared experience is necessary to prevent barriers to understanding:

> In most cases, the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship.

Oakley, (1981) cited in Tang, (2002 p.704)

The identification of similarities and differences between the researcher and the participants of this research has therefore been considered. The participants in this research were all white, English speaking and from working/middle class backgrounds – similar to the researcher. The participants were aware of the reason for the interviews (for research leading to PhD qualification) and understood what this was, that the interview was linked to a University and academic achievement and all supported the concept as such. Data on sexual orientation was not collected and was not thought to affect the quality of interview, nor the rapport between the researcher and participants. Certain personal information regarding the researcher was shared with participants, such as the fact that she had children, had elderly parents and a relative with dementia, which the researcher felt assisted in creating a shared identity as suggested by Tang, (2002) to form the basis for rapport and the sharing of experiences. The location of the interview was also considered an important aspect in the formation of rapport between the researcher and their subject. Tang, (2002) suggested that interviews which take place at the home of the interviewee are more relaxed and intimate and provide an increased richness of data because the participant feels some power from being on home turf, despite the power the researcher possesses in directing conversation. All interviews conducted in the course of this research were conducted in either the participants own home, or the home of their care recipient and generally occurred in the evening which lent itself to an intimate setting to allow the relaxed development of rapport and the collective enterprise of intersubjective understanding. Kvale, (1996) agreed that the rapport between researcher and participant develops throughout the time spent conducting the research. A research interview is *"not a conversation between equal partners"* (Kvale, 1996 p.6) because the interviewer holds the power to define the situation, the conversation and direct the course of the conversation throughout (Kvale, 1996), building rapport to invite the sharing of honest and meaningful

information. This rapport however, may allow a participant to reveal more information than intended or even consented to due to a perceived relationship beyond that of researcher and researched. Chase, (1996 p.57) surmises the problem as *"an informed consent form cannot possibly capture the dynamic processes of interpretation and authorship".* The researcher remained aware of this problem throughout the research and was conscious of its possibility but no issues were identified throughout the research.

The ethical guidelines associated with research institutions are of paramount importance in the consideration of the ethical standpoint of completing research (Hopkins, 2007). In response, approval for the completion of the research was sought and granted by the Hull University Ethics Committee. The University of Hull ethical approval process indicated four key ethical areas for consideration: Potential harm to the participants; Informed consent; Invasion of privacy; Level of deception. The research was conducted with the best interests of the participants as primary consideration and was conducted truthfully and with respect. Participants were treated with dignity and their right to privacy and confidentiality was protected at all times. Participants were given key information regarding the project including general aims and objectives, data collection and analysis techniques, data storage and future use, in paper format. Participants were also given an informed consent form, which they were required to sign before being included in the research. Physical signature was possible for each of the participants. Participants were made aware that they have the right to withdraw their consent at any time. A prerequisite in the inclusion criteria required all participants to possess the cognitive ability to provide consent.

The research involved the interviewing of some elderly (65 years+) participants, as well as the individuals who provide them with care. Each participant was briefed prior to the interview to define the research subject and purpose. This briefing also provided explanations and reassurances regarding the interview process (including audio-recording) and explained confidentiality stipulations and the fact that the interview could be terminated at any time. No information was withheld from participants prior to interview and the interview process did not pose any risk to the participant's physical health. However, the care

recipients rely on their informal carers, often for daily living activities and so may have been reluctant to reveal negative aspects regarding their care experiences for fear of reprisal. To address this, participants were provided with confirmation that the information given in interview would remain confidential and would not be disclosed to others, including other members of their ECE. This also served as a strategy for building trust and confidence in the researcher. The researcher also emphasised free-speaking in interview, with participants able to request that certain aspects revealed in interview would not be transcribed if they so wished. As well as providing an opportunity for intersubjective clarification of meaning, follow up interviews allowed participants the opportunity to read the transcript of their interview and request any contentious sections be withheld from final write up.

The research focused on the lived experience of the participants and as such discussions of this nature could potentially have resulted in negative feelings and emotions for participants, particularly in dealing with what is for some, a highly emotional subject. Debriefing after interview took place to address this and included signposting to other services including their own General Practitioner, counselling services such as the Hull-based 'Let's talk' service (commissioned through the NHS) and private service providers such as Cruse Bereavement Counselling and East Yorkshire Counselling Services. All participants spoke English as their first language and so ethical considerations regarding the use of interpreters was not required, however all participants were given explicit information regarding how their data would be used, stored and disposed of.

One key consideration for the University of Hull Ethics Committee was the issue of consent – namely an individual's ability to provide fully informed consent for research purposes. Josselson, (1996) suggested that informed consent actually prejudices the outcome of the research because the provision of information such as aims, objectives and methods imposes the researcher's perspective onto the research participant. The utilitarian approach suggests that it is ethically correct to complete research without informed consent as the research did not cause direct harm to participants and may well result in increased utility for the wider population. However, Kantian Deontology dictates the use of full

informed consent to ensure the autonomy of the decisions made – in this case, to participate in the research or not. The very existence of a consent form can also be misleading, particularly to more vulnerable groups who may see the form as a legally binding document which gives the researcher the authority to pose any question, gather any information and use it in any way he/she deems appropriate. The ethical bearing of this research however required the participants to provide fully informed consent through the completion of an appropriate form in all cases. All participants other than those in the 'S' research group (see table below) fully completed the researchers consent form. It was not necessary for any adaptions to be made to the consent form (such as an audiological recording of consent). Consent was made implicit in the case of the 'S' study group.

The research used the letters 'R', 'U' and 'S' to identify the origin of the study group to which the participant belonged. Each ECE was then given a number within the study group and each participant was then given a unique letter and number identifier which provided the researcher with information pertaining to that participants study group and relationship with the care recipient in that ECE. (For example, R1S1 identified a participant in the rural study area, Group 1 who was the eldest son of the care recipient). Pseudonyms were used for the identification of individual participants within the findings and discussion section of the thesis and were not sequenced in an effort to further protect the identity of those involved.

3.3. Data Collection

Data collection took place via semi-structured interviews with members of the ECE individually. An interview guide was produced by the researcher to indicate the topics to be covered (Kvale, 1996), however, interview style was open and replicated natural conversation; the most appropriate method for eliciting a story (Abma et al., 2012). Participants were provided with information to contextualise the interview beforehand, methods and process were defined (Kvale, 1996) (such as explaining that the researcher would take notes and that the interview would be recorded on two separate audio devices) and were debriefed after the interview to manage any resulting tensions or stress for the participant, to signpost to further services if required and to clarify the main points of information.

A further re-interview took place with some participants (some declined the offer and some participants were unavailable for follow up). This second interview was completed after transcription and was used to confirm the meanings of the data identified and to develop the intersubjective, collective understanding of the interview – Kvale's (1996) self-correcting interview.

The interviewer used open ended questions which were brief and simple to stimulate conversation on the chosen topics and utilised introducing questions, follow-up questions, probing questions and interpreting questions (Kvale, 1996) to ensure responses were spontaneous, rich, detailed, transparent and verified throughout the interview.

The interviews were audio-recorded by two independent sources and then transcribed verbatim by the researcher alone. Audio files were imported into NVivo software system to be stored securely and the two original audio recordings deleted once quality checks had been performed on the NVivo version. Field notes were also collected by the researcher which included general impressions, observations of the participant and their home, the experiences of the researcher in conducting the interview, any data collected either prior to or after the audio recording and notes for clarity such as basic family structures etc. The field notes were written by hand at the point of data collection but were then inputted into the NVivo database and the originals destroyed in line with Hull University confidentiality policy. Mason, (2002)

confirmed that transcripts alone are inadequate in recording non-verbal aspects of the interview because the researcher ultimately decides which utterances, body language expressions and emphases end up as text in the completed transcript and so the field notes were included as a data source during analysis. Kvale, (1996) agrees with the importance of field notes during the interview process and suggests that the interviewer's active listening and the remembrance of the nuances in the interview act as a selective filter for retaining the very meanings crucial to understanding the phenomenon being studied.

Data security was guaranteed by the storing of data files on a password-protected computer and backed up using an encrypted memory stick which was then stored in a locked box at the researcher's home address.

Paper records of the interviews, including consent forms, personal detail forms, etc. were scanned into electronic format and saved via encrypted devices and the paper originals shredded and disposed of in line with University confidentiality policy.

As previously described, all participants (including the CAG statements) were given anonymous letters and numbers to identify each research ensemble (ECE) and pseudonyms were used for the identification of individual participants. The master copy of real names, ECE numbers and pseudonyms was stored electronically on password-protected and encrypted devices.

3.3.1. Problems with data collection

Due to the nature of the interviews and for security reasons, all the interviews conducted were in the home of the participant or their care recipient. This allowed the minimisation of background noise for recording purposes and allowed the participant to be more relaxed. However, the settings for the interview did produce problems. Firstly, the security of the researcher was a potential issue which was dealt with via a pre-agreed arrangement with the researcher's supervisor. The interview location, time and date were given to the Supervisor and a system of 'text-in, text-out' agreed. A timescale of 2 hours was allotted as a maximum time for interviews, after which the Supervisor agreed to raise alarm if no contact had been made after this period. Any interview which

legitimately took longer than the two hours included a text to the supervisor to allocate extra time prior to security arrangements being implemented. A further issue resulting from the location of the interviews was the occupancy of the participant (usually the carer) and the care recipient in the same room whilst the interviews were conducted (which occurred on three occasions, although one care recipient was both blind and deaf). The researcher did not wish to challenge the arrangement in an effort to build rapport with the participant and because of the practicalities of relocation (often the care recipient was not able to be left alone for the time needed to conduct the interview). Although this may have resulted in moderated disclosure regarding certain aspects of the interview, it also provided an extra dimension whereby carer and cared for sometimes, and on certain subjects, explained their experiences together, creating increased intersubjectivity with the researcher.

A further problem in data collection was the potential barrier of the audio recording equipment. Participants often began to disclose their experiences prior to the audio recording device being switched on or after the interview had been seemingly completed, and the recording device switched off. To manage this, the researcher took detailed field notes to capture the data not recorded on the recording device which was then included in data analysis.

As previously stated, the researcher did attempt to re-interview each participant to clarify meanings produced through the intersubjective process. This was not always possible however as some participants refused the second interview, a number had moved house and were lost to follow up and one participant actually died shortly after interview. Re-interview was also not possible for participants in the 'S' study group and so re-interview occurred for 10 of the 31 data sources.

3.4. Data Analysis

Data analysis is a practice undertaken to enable theory generation (Tavory and Timmermands, 2014) and data analysis descriptions are required to provide evidence that a rigorous and valid method of data analysis was employed on which to develop theory (Gummesson, 2005), considering that *"theory is the currency of our scholarly realm"* (Corley and Gioia, 2011 p.12). Kvale, (1996) identified five steps of qualitative analysis; subject description of their lived world; discovery of new relationships during interview; condensation and interpretation of meaning; transcription interpretation by the interviewer; re-interview to clarify meaning. These five steps formed the basis of data analysis for this research.

The data in this study was analysed using the principles of abductive analysis. Abductive analysis is a qualitative analysis tool which is aimed primarily at theory construction – a possible explanation of why things happened the way they did, and not facts, like inductive and deductive approaches (Tavory and Timmermands, 2014), which supports the phenomenological approach of the research.

> Theory is a statement of concepts and their interrelationships that shows how and/or why a phenomenon occurs.
>
> Corley and Gioia, (2011 p.12)

Whereas inductive analysis approaches focus on the identification of new cases within existing theories and deductive approaches seek to test existing theories, abductive analysis seeks to produce new theory from research data that does not fit existing theory.

The semiotic perspective of abductive analysis uses a triad of sign, object and interpretant, the sign being the signifier that there is observable actions, the object being the 'thing' (person, actual object or even idea) that the sign points to and the interpretant – the person observing the sign-object and producing meaning from it (Tavory and Timmermans, 2014), the triad being temporal and exclusive to those involved in its formation, and a continuous process.

Abductive reasoning is reputed to address the weaknesses associated with both inductive and deductive approaches;

> Deductive reasoning lacks clarity in terms of how to select
> theory to be tested via formulating hypotheses. Inductive
> reasoning, on other hand, [is] criticized because no amount
> of empirical data will necessarily enable theory-building

Dudovskiy, (2017 p.1)

The method involves the identification of unexpected empirical research findings that have not been explained by the existing range of theories, which are then developed into speculative theories through systematic analysis (Tavory and Timmermans, 2014).

Abductive analysis can be layered, creative and revolutionary; is by definition incomplete, and the objective of identifying simplicity in potential theory is actually complex (Thagard and Shelley, 1997). Abductive analysis moves back and forth between observations and theory, identifying knowledge and seeing if the new research adds to what is already known, alters what is already known, or generates new theory which can then be subjected to further testing through further observations (Tavory and Timmermans, 2014).

For the production of this thesis, the qualitative analytical software NVivo was used as a tool for organisation and clarity. Transcriptions of the audio recordings of the interviews were produced within the NVivo software whereby the researcher alone listened to the audio and typed the words spoken verbatim within the software. Pauses, utterances and inflections were also transcribed as accurately as possible. Field notes, memos and other observations were also typed up within the NVivo software. Although consideration to using the software to generate coded entries was considered, the researcher decided to manually code entries in an effort to become further familiarised with the data; to begin the process of analytical thinking and also to identify early on in analysis any observations that did not fit with existing theory. Open coding was used to identify observations which formed potential themes, followed by axial coding to *"examine a promising theme in the observations by looking across data sources to flesh out key conceptual dimensions to account for variations"* (Tavory and Timmermands, 2014 p.54). Throughout analysis, conceptual maps of emerging theories were produced in paper format which then informed selective coding to flesh out one particular theme at a time. The coding process illustrated above was implemented for all data sources including the transcripts

of interviews, statements provided by the 'S' study group and all observational/field notes and memos. In this way, the data was analysed abductively – although the data identified many interesting themes, it was only those considered new or surprising and that had not been considered in existing theory which were developed fully and used as the basis for the development of the theoretical model to explain identity transition in carers.

This repeated coding process assisted in the protection of the data against biased memories and preconceptions (Tavory and Timmermans, 2014) and assisted in de-familiarising the data so that the phenomenon could be experienced afresh, to *"question the relation between the sign-object and our habits of thought and action in producing an interpretant"* (Tavory and Timmermans, 2014 p.57).

To demonstrate transparency and to fit the epistemological approach of the research, participants own words were used in the findings section of this thesis as much as possible to demonstrate and evidence the emerging theoretical tracks.

The table below identifies each of the participants included in the research. Information provided includes the participants' relationship to the care recipient, gender, age (if known) and ethnic classification (if known). This information is important for the researcher to understand the starting point of the lived experience of the participant – for example a son of 30 caring for his elderly black Mother may have a very different lived experience than a wife of 70 providing care for her elderly white husband. The demographic information was not used for data analysis purposes or for the production of findings, but merely acted as background knowledge to assist in the phenomenological approach of the research. Because of the nature of the acquisition of the 'S' study group, demographic information was only available where it had been revealed by the participant in the statement provided.

Table 1 - Participant Relationships and Demographics

ECE Number	ECE Identifier	Participant Name	Relationship to Care Recipient	Gender	Age	Ethnic Classification (ONS, 2001)
R1	R1CR	Robert	Care recipient	Male	71	White British
R1	R1S1	Edward	Son	Male	45	White British
R1	R1DL	Karen	Daughter in Law	Female	43	White British
R1	R1S2	Chris	Son	Male	42	White British
R1	R1SL	Diane	Sister in law	Female	72	White British
R2	R2CR	Catherine	Care recipient	Female	88	White British
R2	R2N	Margaret	Neighbour	Female	63	White British
R3	R3H	David	Husband	Male	64	White British
R4	R4W	Ashleigh	Wife	Female	71	White British
R5	R5W	Francine	Wife	Female	74	White British
R6	R6H	Bob	Husband	Male	68	White British
R7	R7H	Ian	Husband	Male	81	White British
U1	U1CR	Dorothy	Care recipient	Female	88	White British
U2	U2DL	Katie	Daughter in law	Female	52	White British
U2	U2S1	John	Son	Male	54	White British
U3	U3D1	Jill	Daughter	Female	48	White British
U4	U4DL	Emily	Daughter in law	Female	46	White British
U5	U5D1	Jayne	Daughter	Female	56	White British
U6	U6H	Fred	Husband	Male	74	White British
S1	S1H	William	Husband	Male	N/K	N/K

S2	S2H	Harold	Husband	Male	72	N/K
S3	S3H	Gary	Husband	Male	N/K	N/K
S4	S4W	Gwen	Wife	Female	66	N/K
S5	S5W	Yvonne	Wife	Female	N/K	N/K
S6	S6W	Vivienne	Wife	Female	65	N/K
S7	S7W	Tracy	Wife	Female	N/K	N/K
S8	S8H	Tim	Husband	Male	75	N/K
S9	S9H	Brian	Husband	Male	N/K	N/K
S10	S10W	Carol	Wife	Female	70	N/K
S11	S11W	Susan	Wife	Female	N/K	N/K
S12	S12S	Neil	Son	Male	49	N/K

Consideration of the demographical information regarding the nature of the relationship to the care recipient revealed that the majority of participants were spouses of the person they cared for, although a substantial number of adult children were also participants. The proportion of male to female carer participants was evenly split, however a higher number of carer participants provided care for a female care recipient, rather than male. Although information regarding participants' age was collected in interview, information regarding age was generally not available from the 'S' participant group. The age of most carers, however was between 70 and 79 years of age, suggesting individuals of pensionable age.

This chapter has identified the researcher's ontological and epistemological position and described the methods used in the production of this thesis. A phenomenological approach has been adopted to provide a description of the phenomena studied, but to also allow the attachment of meaning and theory production. Following the chosen methodological approach, intersubjective interviews were chosen as the method for the generation of data and (in line with both the methodology and methods undertaken) abductive analysis used to identify new and differing theory.

The next chapter identifies the findings of the research and considers them in terms of the transient nature of the carer identity, when and how these change and the effects changes in identity have on others and on the carer themselves. The quotations used from participants are verbatim and thought-provoking but are also sad at times and distressing on occasion.

Chapter 4. Findings

This chapter begins by identifying the concepts of distance highlighted by participants. Geographical distance has been documented in the literature as affecting informal care relationships, but this research has clearly identified that there are in fact multiple concepts of distance that affect carer relationships and identity. Data is provided which supports the formation of these concepts.

However, the data showed that the most consequential form of distance for impact on identity is that of emotional distance. Due to constraints of time and length for the production of this thesis, other concepts of distance are identified and evidenced in brief, however the major content of this chapter focuses on emotional distance.

The section considering emotional distance describes the experiences of the carer and care recipient participants in providing or receiving informal care. The section is divided into six sub-sections; firstly, participant experiences are identified that indicate the desire to escape their carer/cared for roles and the reasons why they desire this, including the effects caring has had on their own health, their ability to participate in activities outside of the caring role; including any involvement of other family members; Secondly, participant experiences are described in situations whereby the carer desires closer proximity to the caring role and describes how participants attempt this through communication and involvement of the wider family, the use of possessions and the utilisation of rituals to decrease emotional distance; Thirdly, participants describe how their caring identity affects them personally including changes in their character and their relationships with both the care recipient and others. The fourth section considers motivations for caring such as love and obligation and how differences in motivators influence the adoption of the carer identity. The final sub-section considers how in certain participant examples, the caring and cared for identity can be taken to the extreme. This findings section clearly identifies and provides examples of the concepts of distance associated with caring, but also demonstrates the transitional process of self-identity when informal care commences or changes.

4.1. Concepts of distance

The data demonstrated four concepts of distance affecting caring relationships. Firstly, geographical/physical distance – the actual distance between members of the ECEs or between care recipients and services and amenities. Geographical distance affected carer identity because it affected the carer's propensity to transition from their previous self-identity to that of carer.

4.1.1. Geographical Distance

The value of geographical proximity seems to be of particular importance in times of crisis, when an action response is required of the ECE. For Ian, this was important when his wife became ill and had resulted in his children being named responders in the 'lifeline' system (an emergency button worn around the neck by vulnerable people in case of an emergency). Ian reported that he found the proximity of the ECE an advantage, allowing increased frequency of contact. This is supported by Emily whom also felt close proximity was important in times of crisis, such as her Mother in law being unable to lift her Father in law:

> Our daughter round the corner… She's been here and has been able to come round at crisis times, like when Pam had her stroke... I wasn't sure whether to phone 999 and I thought I'll have to, but I rang Louise and she was round here like a shot and when I had to take Pam to hospital with this frightful heart attack when she nearly died, Louise again came round and helped there.
>
> [Researcher] So it's important to you to have someone geographically close, for the crisis times?
>
> Oh yes. And I believe on the Lifeline, the 2 or 3 local children are on the Lifeline thing.
>
> [Researcher] So how does it feel having all of your children living so close?
>
> It's nice they are round here. We can see them so much more. If we have to go into hospital they can all come to see you at the first sign of a problem. They then get themselves into a rota for visiting.
>
> Ian

> The good points is that we are really close, a few minutes' drive so if we need to get there we can. If we didn't live here I don't think we'd be able to go as often. And she wouldn't like that, at all. Like there was a time the carers didn't turn up by 9 o clock at night so she rang Richard because she needed to sit Alex up but she couldn't do it herself, so Richard went round to help her. So that's the bonus of it I suppose, that she's really close, so for anything, we can just pop, if we need to. So close proximity is better, easier. I think if we were further away it would be much harder.

> Emily

Optimum distance between ECE members was subjective according to the situation and needs of the individuals involved. Bob moved from the South to be closer to his parents, but baulked at the idea of them being too close:

> [Researcher] Where do your parents live?
>
> In York, so it is quite a trek to get there.
>
> [Researcher] Would it be easier for you if they lived closer?
>
> No, I'm quite grateful that I live quite far away! I mean to say, it was one of the things when we moved up here, because we used to live in Swindon, we wanted to be within travelling distance of them, but far enough away so that we weren't on top of each other, and it's just about right, this distance.
>
> Bob

Ian also identified negative consequences of living geographically close to the ECE, despite reporting a close and loving relationship with all members. Ian implied that an ECE that were geographically close allowed greater opportunities for invasion of privacy, interference and the loss of autonomous decision making.

> It's a strange thing actually because in some families where there is some distance, you don't have a problem because you don't have that ... independence problem because they're not close enough to interfere too much, on the other hand, when you do have them close to hand they do tend to interfere, I don't like to use that word, but interfere in a nice way to do things
>
> Ian

Different expectations were also revealed when geographical distance between ECE members differs. Jayne felt that the more contact she had with her elderly Mother, the more was expected as a result of now living geographically close. Jayne felt that this was to the detriment of her own personal life, however still made it her own responsibility to visit her Mother 3 or 4 times daily. Jayne contradicted herself in stating that she did not revisit once she had gone home, but then admitted to revisiting her Mother even when she had gone to bed to ensure her wellbeing and previously confirmed that she was the named

individual on her Mother's Lifeline system and so would attend to her Mother during the night if the need arose:

> The more I come and spend 2 or 3 hours in the afternoon, the more she wants, but once I've gone home, that's it till the next morning… to be fair, I haven't got a life… So now she has a tea call on Saturday and Sundays, so I get a little break, although I still come across about 10 ish and make sure she's tucked in. Because she gets in to bed and doesn't cover herself up properly, so I like to check, so she doesn't get cold.
>
> Jayne

Edward felt that increased physical closeness allowed increased physical interaction which he valued more than remote contacts such as via telephone. For Edward, conversation was easier face to face and implied a greater value on the quality of this form of contact.

> We see him more on a physical level. So we see him maybe 2 or 3 times a week in person and so if we're sat in a room with my Dad you can get a conversation out of him, And he's committed to talking with you, you know he can't say oh well I'm off now and put the phone down, cos you can't do that in front of people. So in that respect... but then I suppose Chris speaks to him every day just to make sure he's alright.
>
> Edward

Emily lived geographically close to her Mother in law, but longed for geographical distance for a short time, in the form of the family's annual holiday abroad. Emily's expectation of this however was tempered by the expectations of her Mother in law which lent tension to the relationship between them. Emily described feelings of guilt at the consideration of going on holiday, implying that the level of negative emotion outweighed the positive ramifications of going on holiday, achieving geographical distance from the caring situation and taking a break from the demands of the caring role. Emily also implied that the cost of missing out on the annual family holiday would be felt by all members of her family, including her two young sons:

> But we wouldn't go abroad now, the guilt would be too much, which is a shame because we liked taking the boys abroad, you know getting right away. We can't do that now, get that kind of distance from it all, we just have to keep going and going with it all.

Emily

Jayne described issues related to being geographically disparate with her Mother previously, and expected that her Mother should be the one to take action to remedy the issues associated with living at opposite ends of the same city. Jayne's Mother had lived in the family home for 40 years and felt emotional attachments to both the house and the residential area, but left this house to reside in the same geographical area as her daughter. Jayne obviously felt some guilt at this, as she implied firstly that she *"encouraged"* her, then admitted to *"pushing"* her. Jayne was also quick to confirm that other ECE members had also been involved in the decision, helping to minimise any guilt that Jayne felt regarding the house move:

> [Researcher] And what was it that made her move?
>
> To be closer to where I live, I live just round the corner, a couple of minutes away, literally round the corner…I was kind of prompted to encourage her to move, because she had been poorly off and on and it was too far to come. It was a 15 mile round trip… It was that really bad winter we had. It was thick snow - that was when I really said to my mam, look this really can't go on, I really can't do it…But that's what pushed us to move her, because I said, I don't know, next year next week I might not be able to drive, then how would I get down to her…Our Jez said the same; that she couldn't go on like that being at that end. Because like, I'd get lifeline ringing me up, its 7 miles to get there, across the city. It's not always a case of being able to do it.
>
> Jayne

Participants explained that the type of assistance and/or support provided by ECE members who live far away was different to that given when the ECE was close by. Karen described how her brother-in-law Chris had a greater frequency of contact with his Father and thought that this was because he lived further away from him. Karen implied that because the practical support he could provide was limited, Chris felt guilty and to make up for this, increased the frequency of remote contacts with his Father. Karen's feelings were echoed by those of her husband Edward, and Chris suggested that geographical distance between ECE members led to emotional distance (which needed attention and affirmation, addressed through frequency of contact to minimise this emotional

distance) – an issue which was not experienced when living geographically close according to Chris:

> Chris has a different role. Ermm because it's a 3 hour drive away
>
> [Researcher] Do you think that frequency of contact, is affected by how far away you live?
>
> Yeah, I think Chris wants to feel closeness with his Dad, so to keep the closeness I think he phones him every day, only maybe 2 or 3 minute conversation while he commutes to work, 'how was your day, what are you up to…' but I think Chris finds it a struggle that he can't get down as much … but he's doing that because he feels guilt that he's so far away. .. And I think that's because of the distance. Because... [Robert] might have phoned Chris and said 'I am going to go look at sofas with Karen and Edward,' I think that's what he'll have done, but I don't think he asked Chris for any input. Because it's not like Chris can come with him, you know… Yeah I think it was the distance more than anything, but I know when we first lived there, Chris would often ring Edward and say that he felt bad that he couldn't be more, up there more you know.
>
> Karen

> Obviously there's a ...250 mile distance between the 2, so my brother phones every day. He got into a routine from the early days. Whereas, he might not see him for 5-6 weeks. So he phones every day and the conversation will be not about a lot, because you don't get a lot out of my Dad, so just general chit chat and that'll be that.
>
> Edward

> It's strange actually because I know Edward is a lot closer geographically but when you're that close you don't need to be confirming it, so I probably speak to Dad more than Edward does…And it's difficult for him to rely on me too much because I'm so far away, anyway.
>
> Chris

Participants revealed that living in the same house as the person they cared for meant a lack of physical distance between them. Tensions between the carer and care recipient were common, often due the carer desiring more personal space and the care recipient wishing to spend more time close to their carer. Both Susan and Carol cared for their husbands and found that the increasing

need for physical closeness of their care recipient resulted in frustration and a greater desire to increase that distance:

> Now Norman wants to be by my side at all times so doing things on my own or with my Granddaughter need careful planning and organisation so that someone is with him. He cannot be left alone for much more than half an hour.
>
> Carol
>
> He likes to 'help' so will stay with me while I sort laundry, load the washer or dishwasher, fold clean clothes and put them away. Since he cannot be left alone there are many things which I cannot easily do…
>
> Susan

Jill told a story regarding her Mothers increasing reliance on her Father, particularly in surroundings that were less familiar Jill told the story with humour, however expressed real concern regarding her Fathers increasing frustration with her Mother – how he is unable to get any space from her and ends up shouting at her. Jill told how this was never the case before her Mother became ill and how both parents led independent lives from each other prior to her illness:

> We go on holiday we go to the same place every year. We go down to Torquay, the same hotel each year and the last few years we've been, she doesn't go anywhere on her own because she gets lost. And we know that place inside out so... I don't know if things like that maybe worry her. I think one year we went on holiday my Mum and Dad have their own room and my Dad had said to her, I'm just going to pop down to the car and collect another bag from the car and he was gone maybe 10 minutes and when he came back she really had a go at him saying 'where have you been, you've left me on my own', So I do think... when my Dad's there, she's totally reliant on my Dad, she follows him around. One time we were at the service station, he went to the loo and he said just wait here outside and she followed him into the gents! [Laughs]. She's completely ... he says she follows him everywhere, he is like her focal point if you like…I've said to him, 'try not to, try not to shout at her because it's not her fault' and he understands that but sometimes I understand it's difficult when you're there 24/7. I think she can get annoying, I mean my Mum and Dad were always quite independent when they were younger, I mean my Dad would have his thing and my Mum would do her thing and then they'd do things together, but no, she's with him all the time.

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He doesn't like to go out and leave her on her own for too long

Jill

The participants revealed that one of the most significant aspects of their caring role is that it is 24/7 – that they do not have the luxury of leaving the caring role at the end of the working day and so feel taken over by their caring role, that they have no life of their own and that their own needs are eclipsed by those of the person they are caring for. Their ability to get some distance from their caring situation is severely hindered:

I can't walk away from it, it's not like a paid carer or a job where you go home at night. Its 24/7 full on and I don't think it's right. There's got to be changes. We can only live in hope.

Ken

It's not easy looking after someone - your life is no longer yours…When things get on top of me there's nowhere I can go to get away. Sometimes I just want to run away.

Vivienne

Professional carers have the luxury of going home at the end of the shift or bad day, putting their feet up and maybe having a bath and a glass of wine. It is much harder when you're working day has no end and the one you care for is with you 24 hours a day.

Yvonne

Ashleigh, who cared for her husband until he died, felt that she was always 'on call' with her caring role and felt frustration at the lack of distance from it she was able to maintain. Although Ashleigh told her story in a light-hearted manner, it was clear that the frustration she felt was very real. Ashleigh attempted to secure physical distance by moving her husband's bed downstairs whilst she remained upstairs, however this did not stop the demands of her husband and failed to provide her with any real space:

We made a proper bedroom in there [in the downstairs dining room] for him but he was... it was a case of once he was down here "are you there love???" [Interviewee shouts towards the upstairs, impersonating Tom] "Yes", "are you putting kettle on??" "No!!!" I'd sit here and think I've just been

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down, I've just done so and so... "What time are we having tea???" [Laughs]

Ashleigh

I remember, I brought him a Satnav for his birthday one year, and my bedroom is above his and I thought who is he talking to downstairs? I can hear him talking to somebody, but it was the Satnav! All of a sudden, I heard her say "you have reached your destination"! I came down and said what on earth are you doing? Oh he said, it's good is this! Do you know what time it is I said, will you turn the damn thing off! [Laughs]

Ashleigh

Ashleigh also expressed frustration that when she did manage to escape the house, she remained unable to get distance from her caring role as her husband used to telephone her – obviously tense regarding her absence. Ashleigh expressed her frustration at the situation, particularly when they installed further telephones in the home allowing him to telephone her upstairs, from his bed downstairs:

> But if I went out anywhere, like shopping, I didn't have much of a social life but I'd get a phone call, where are you now? I'd say I'm in the shop, How long are you gonna be? When are you coming home? I'd say I've left you a sandwich in the fridge, oh well I'll wait till you come home he'd say.

> [Researcher]How did that make you feel?

> Aaaaarrrggghhhh! Because I used to think, I haven't been out an hour and he's already wanting me back home! It wasn't that he couldn't cope on his own. He was able to make a cup of tea, so he was never... but in an afternoon he used to have a good sleep and that was my time.

> [Researcher] Why do you think it was that he was ringing you when you were out shopping?

> I think it was just that he felt more confident or more relaxed when I was in. Now I'm on my own I understand how he felt, what it's like to be on your own, but I mean he wasn't on his own really, the most I left him was 2 hours or so… These phones (gestures to the house telephones) we had one in my room and one downstairs because with these he could ring me upstairs - are you awake he'd say, I am now! It also had a loud speaker so he could hear better.

[Researcher] Did he ring you up much then?

Well yes, he'd ring and say, what are you doing? What have you done? Can you come down? My bag needs changing!

[Researcher]So were the phones a bit of a curse for you?

Yes, well yes they were. And also it was always at the side of his bed.

Ashleigh

Bob confessed that he felt increased pressure to be with his wife physically as much as possible, due to the possibility of her falling. He admitted that he felt frustrated with this, even though he loved his wife a great deal and looked for methods for dealing with this enforced proximity. Bob also alluded to feelings of guilt if he did go out, stating that his wife would be too afraid to move very far without him. He also disclosed feelings of irritation and tension between him and his wife as a direct consequence of physical proximity enforced through the caring circumstances. For Bob, ways to increase physical distance included relocating to a different floor within the house for part of the day. In this way Bob felt some physical distance between himself and his caring role, but felt comforted that he was physically close in case of problems:

> If she falls she cannot get up on her own, she needs someone here to give her a hand. So I can go out for a little bit and know that she can just about get to the toilet down here on her own and back, but she doesn't tend to move much if I'm not here. Because there's that fear… It's all about doing things as quickly as possible so I can get back to Sylvia in the quickest possible time.
>
> [Researcher] So you spend the vast majority of your days together - how does that effect your relationship?
>
> We get irritated with each other. I must admit, what I try and do is I try and spend part of the day upstairs with the computer, doing either Council business or mustard seed business or, whatever. Just so she's down here on her own. I'm still within calling distance if she needs me, but we are actually separate. Sometimes it's just a case of that's all it needs. Sometimes it's a case of one or both of us want to have a sleep in an afternoon! {Laughs}
>
> Bob

Ashleigh felt that the utilisation of different rooms in the house allowed a sense of physical distance between the carer and cared for, despite neither party actually leaving the house. Ashleigh and her husband went so far as to name rooms as his or hers, creating a sense of ownership and therefore distance between carer and cared for:

> He used to have a couple of friends that would come and see him. We've got a conservatory at the back which we used to call Tom's room, and I used to leave them to it in there.

> Ashleigh

Francine explained about her husband's active life as a farmer prior to becoming ill. She acknowledged that both of them were used to physical space, despite both working on the farm. To maintain a sense of this and to provide physical distance between them, Francine encouraged her husband to use his mobility scooter to go out in the garden when the weather was clement. So important did Francine feel this was that she actually put down carpets in the muddier aspects of the garden for her husband's scooter:

> Because in summer it's alright, he goes round the garden on his mobility scooter, but at the moment it's terrible! I've put bits of carpet down in the worst bits but the scooter churns up the grass... I need more carpets for the garden! I'm sure there must be some in the loft!

> Francine

Neil moved his Mother into the home he shared with his wife when she became too ill to care for herself. He kept a diary of this time period and was willing to share it with the researcher. The act of moving his Mother into the familial home caused a great number of tensions between the ECE members, not least his sister and wife, who both struggled to deal with the situation and his Mother's decreasing mental health. Neil was first relieved that the decision to co-reside would remove some of the problems faced whilst she lived independently, but tensions due to physical proximity soon manifested and the ECE, (in particularly his wife Judith) had to find ways to increase physical distance between herself and the caring situation at home. Neil's wife even stalled her planned retirement from employment so that she could escape from the caring situation each day. Neil obviously feels great pressure at trying to separate his wife and Mother in

the confines of one household and his wife used her social network to remove herself from the situation during *"intolerable"* evenings:

> She moves in with us - can delay it no longer…The amount of time I am spending with Mum makes her look to me more and more. This creates jealousy from my sister…Relief that, now she lives with us, the worry that she will have bought something from a cold caller (a new roof, a burglar alarm system, more Rington's tea when she has enough for the next 2 years in the cupboard already - we had them all) is now gone.
>
> Neil

> My wife's intended winding down towards retiring from her mobile hairdressing business is on hold because it provides relief from the pressure…Judith went out in the eve to get away after Mum was abusive and swore at her…Weekends are intolerable. Having to keep Mum away from Judith and be ingenious in thinking of ways to cope. I am past caring sometimes…Mum got angry and abusive to Judith who had to go out for the evening to calm down.
>
> Neil

Participants revealed the use of certain possessions which assisted them in attaining physical distance from their cared-for. Gwen confirmed the value of having a car in an attempt to remain active and interested in external aspects of life. Because the car was modified to be used for individuals with disability, she was able to get her husband *"out and about"*, implying that to her, the ownership of a car represented a certain freedom and ability to moderate the actual physical distance between herself, her husband and other aspects of their life:

> My husband takes strong painkillers so he sleeps late in the mornings and often has a sleep in the afternoon as well, so my options are limited. We have a car on the motability scheme so it does mean we are able to get out and about if he feels well enough, which is very handy.
>
> Gwen

For Ian, the loss of his ability to drive affected his opinion of his own independence and he referred to it as a *"challenge".* To address the issue, he added his daughter to their car insurance policy. Ian suggested that this gave them increased freedom to *"go a bit further"*, however expressed concerns regarding driving quality. It seemed that Ian would have much preferred to

undertake the driving himself but has admitted to slowing of his reflexes and sensibly, sought alternative arrangements. However, Ian revealed that the idea actually came from his daughter and not himself, suggesting that it was done with some reluctance on Ian's part:

> She's also licenced on my car so... she's the only one by the way... so she'll come sometimes and take us out, if ever we wanted to do a longish journey, I won't do them anymore so if we wanted to do that she'll come and take us.
>
> [Researcher] How do you feel about that?
>
> Well its a bit challenging. I find that difficult to cope with because I lose a bit of independence there, because having said that I think to myself if we can go a bit further and if we can see the countryside a bit further then its a jolly useful thing to have. And she's a very good driver, a very careful driver… My daughter said look, get me on your licence and I'm quite happy to take you out sometimes. I haven't had any big crashes or anything like that, but obviously one has to take care, one gets a bit slower with age.
>
> Ian

As Neil's Mother's ill health progressed, she became less mobile which helped the family as they no longer had to worry about her wandering off. Neil revealed that they had been able to increase physical distance between themselves and his Mother through the use of technology, using CCTV accessed via a smartphone to check her safety, whilst not necessarily being in the same physical location as her:

> We can pop to the shops without taking her with us - the CCTV in her room (accessed via my fancy phone) minimises the anxiety around leaving her.
>
> Neil

In a similar way, Catherine commended the use of her microwave and tinned foodstuffs with pull-rings that allowed her to prepare her food herself. For Catherine and her ECE this allowed geographical distance between carer and cared for, as meal preparation did not require actual physical intervention.

> We've got tins of soup in, with ring pulls, so I can do those myself if I need to. I'll make myself some toast, a piece of cheese and a full bowl of soup. That would be great. They'll open it then put it in a bowl ready for me, put it in the fridge

> and then I just have to lift it into the microwave. So, we got very good at this.
>
> Catherine

Francine spoke of similar arrangements with the use of her freezer. For Francine, living in a remote hamlet meant that winter months could result in being cut off from shops and services. Francine had learnt to deal with this by stockpiling provisions and utilising her bicycle when the roads were impassable by car:

> Well we've got 2 big freezers, we don't need the food! The biggest problem we've had has been with flooding because there's a bridge over the canal and it dips and that becomes really full and cars can't go through it. It's so annoying really because then you've got to do a great big detour to re-join the road further down. I know once I decided to go on my bike, I put my legs up and pulled myself on the rope to get to the other side!
>
> Francine

Jayne felt a similar comfort when she installed a water boiler at her Mother's house which allowed her to make her own hot drinks without the safety concerns of using a kettle. This resulted in Jayne gaining physical distance from her caring role as she didn't have to be present each time her Mother wished for a hot beverage.

The white goods utilised by Francine, Catherine and Jayne may take on greater meaning to both the carer and cared for, as they change from being merely cooking/storage implements to a method for the maintenance of independence for such a basic need as food and drink provision.

4.1.2. Psychological distance

Psychological distance is defined as *"a cognitive separation between the self and other instances such as persons, events or times"* (Baltatescu, 2014 online). The main themes identified in psychological distance was the possessions and pastimes that participants utilised in their attempt to secure 'mind distance' from their caring identity. Telephones were used by both carer and cared for as a medium for maintaining dependence and therefore psychological distance between the two. The possession of a mobile phone

served as peace of mind for both carer and cared for and allowed psychological distance to the benefit of both parties. In this way, the acquisition of such items was of great importance to those involved.

Robert eventually admitted that his mobile telephone was acquisitioned through pressure from the ECE and admitted that he felt pressure from the ECE to ensure it was charged and switched on. However, other members of the ECE agreed with its importance, but experienced a kind of frustration with Robert that he would carry it around with him, whilst leaving it switched off. This meant that his ECE continued to worry regarding his wellbeing and the psychological distance they were hoping to achieve remained unmet.

> Well, I had a phone, but it was never switched on. So, well… they got me that one, well, I got that one.
>
> [Researcher} Did they make you get that one? Was it their choice?
>
> Yes. A bit of pressure yeah.
>
> Robert

> Well I phone him on his mobile, I've got through sometimes but obviously if he's out golfing or bowling...so that'll be turned off, and he won't turn it back on. He's just got a smart phone so we're just trying to get him to... say to him you know, this is your lifeline and it's not like an old phone, so have it on at all times, and when you're somewhere you should be discreet, put it on silent
>
> Edward

> He has a mobile phone, but the mobile phone is switched off so, you think why on earth have a mobile phone if it's switched off. He's recently got a nice smart phone and there's no reason for him not to have it on.
>
> Karen

John also saw the value of a mobile phone and programmed his Mothers so that she did not have to remember phone numbers. He was also pleased that she actually used it occasionally, helping to keep his mind at rest that in case of problems, she could contact someone to summon assistance.

> Yeah, she does use the phone, she's even got a little mobile now actually, a real basic one just with only a few buttons on

> it. It's just got 3 numbers or 4 numbers and it's if you press 1
> it might ring me, 2 my brother and 3 Katie for example. So,
> she does use that occasionally.

> John

Robert's son Chris recognised that possessions were important to Robert, both as a distraction and as a method for increasing psychological distance from his situation:

> I know he has his lonely moments, and I know he still finds it
> difficult going to bed. Now, I bought him a radio. Ermm, I
> think for his birthday actually, last year. Because I said, look,
> Radio 4, Radio 2, and it's a rechargeable thing and solar
> powered. I keep telling him now, if you wake up in the middle
> of the night, put the radio on, put the World Service on really
> really low, because then you're not thinking about things.

> Chris

The television was also a great distraction for Catherine. It gave her a psychological link to memories from years before when her and her family used to watch together. It was of such importance to her that her ECE knew to avoid specific programme times for their social contacts with her.

> This will make you laugh, recently we got Freeview. I don't
> have Sky or anything, there enough main channels and
> Freeview for me. On one of them they're re-showing MASH,
> which is the most marvellous statement against war, but it's
> funny as well. It's an American Field Hospital, all mobile in
> Korea… And we saw it, we used to watch it avidly, I think it
> lasted over 10 years, everybody watched it. Anyway, I
> suddenly saw, oh, they're doing MASH again and I got
> hooked on it! It's shown in the week days, 7 till 8, so he'll say
> I'll ring before it comes on! That's the only time we are
> limited, otherwise I'll say, carry on I'm eating, but he'll say no,
> I wouldn't interrupt MASH!

> Catherine

Ken felt very strongly that it was important for his wife to have what he referred to as *"women's time"*. He viewed this as personal space for Hayley from the trials of her caring situation and in particular, from him. This suggested that they both needed their own psychological space to *"reflect"*, despite the fact that they generally got on well together.

> I think it's important for Hayley to have that 'woman's' air space, to talk about hair and clothes or whatever. I think having that woman time is important for her and I think for the two of us, I think that it's important for us to have a break from one another. Not that we argue or don't get on, I just think that it's important that you have that time to reflect on your own.
>
> Ken

Bob revealed that he actively encouraged his wife to remain intellectually active and so provided her with outlets to do so. John also saw the importance of an active mind and encouraged his Mother to stay up to date with the newspapers through newspaper USB memory sticks, which would speak the news to her (due to her failing eyesight). Both Bob and John provided active encouragement to their care recipients to maintain psychological distance from their situation.

> I try and get Sylvia to do things, she likes the Sudoku in the newspaper so I get the newspaper; she gets the Sudoku to do daily. She likes to do the crossword so I get her that. If she can't finish it I might have a go at it afterwards, you know. I'm trying to get her to be as independent doing what she can do, rather than... I try and encourage her to do what she can.
>
> Bob
>
> She used to get talking books and stuff like that and I think they used to bring a memory stick in a box and it was like Hull Daily Mail and it'd read all the weeks news and they'd replace it the following week!
>
> John

Ken also disclosed the importance of getting out and about for him and his wife, as a method for attaining psychological distance from their situation. Ken joked that despite their strong relationship, he still desired increased psychological distance from his wife.

> Yes. Because if not boredom would set in for me, I've got to be doing something. We spend most of our time out and about, but it's just within our own airspace, not that we have a problem with that. It's a good job we don't! Sometimes I wish she'd go home on her own like! [Laughs].
>
> Ken

Ashleigh cared for her husband Tom, but unfortunately was diagnosed with cancer herself. Due to the psychological stresses regarding her caring duties and her own health, she felt that a hobby would provide her with a means of attaining some psychological distance. Ashleigh decided to take up designing and making her own greetings cards and exhibited surprise that not only did this hobby give her psychological distance from her caring role, her husband also took interest in what she made, providing Tom with psychological distance from being a care recipient and also bringing them closer together emotionally.

> When I got breast cancer I started to think I'd need a hobby so I started making cards and if I made any cards Tom would always want to look at it to see what I'd made and comment on them. He was always interested in what I was doing,
>
> Ashleigh

The importance of having other interests outside of their caring role was highlighted by Francine and Bob. Both stressed the need to keep their minds active by taking on extra roles such as reader in Church or local council member. Francine stressed that loneliness was a state of mind which could be addressed through taking a strong psychological standpoint.

> I have got other interests, I was a reader in the Church and I did go to a course in York for a couple of years for that and then I again am interested in all things to do with spirituality, so I did another course in the evening for another 3 years back in, 2000 so that was OK.
>
> [Researcher] Do you feel lonely?
>
> Well yes, I have done at times. It depends on how I am... It's more in your mind, you've got to think right and then you'll feel right
>
> Francine

> I've become a Town Councillor, so I can feel that I'm doing something, you know?
>
> Bob

Bob revealed frustration that he did not have the time to pursue those hobbies that allowed him psychological distance, such as painting, where he felt he could *"close everything off"*. He felt his role on the local council served as both a

tool to achieve psychological distance from his caring situation, but also as an intellectual opportunity to *"give something back".* His ability to have defined roles outside of his caring duties provided him with a crucial psychological outlet.

> I have a duty to a lot of people. I get frustrated that there's not enough time for me, to do the things I like to do. I like to paint, but it's difficult to actually find the time when I can just, close everything off and spend a couple of hours painting. maybe because, as I say, I'm duty driven and conscientious I feel very strongly that what I do for the Council, If there's stuff that comes through, you know briefing papers and things like that, that have to be read, I will sit down and read them all. And I will take my responsibilities very seriously for instance I'm the Chairman of the Emergency Committee and that actually covers the flooding. So you know, there's a flooding update meeting for the area on Wednesday and I will spend most of tomorrow preparing for that meeting, getting together background papers and things. So I'm all prepared.
>
> [Researcher] Is that an important role in your life - your Council role?
>
> I think it is yes. It's something that I feel that I can do outside of caring if you see what I mean… and I'm young enough that I can still use my head.
>
> [Researcher] Is that important to you, the using your head part?
>
> Oh yes absolutely. Yes. I like to think! [Laughs] I think without that I would be frustrated. I enjoy giving out, I've spent a lot of my life accumulating bits and pieces of knowledge through my work, through my life and that's all experience in there. And I want to help people to use that experience to better themselves.
>
> Bob

4.1.3. Social Distance

The use of social hobbies and pastimes, socialising with friends and family and enjoying days/meals out and holidays away were communicated by participants as having a profound effect on their lives. The ability to pursue social interests allowed some participants to move away from their caring identity, whilst the inability to pursue social activities was a source of contention for others.

For Carol and Ken, hobbies were a major source of enjoyment before their caring role and was something they did together with the person they cared for. Carol enjoyed varied hobbies including going to watch rugby, line dancing and swimming but since her caring role became more involved, she did not have the freedom to indulge her hobbies. For Carol the issue was the planning and organisation required to provide alternative care for her husband whilst she partook her hobbies. The extent of these issues made the value of her hobbies decrease to such an extent that the hassle of arranging them overtook any pleasure she may get from pursuing them.

> Norman was a keen supporter of a local rugby team and had been going to line dancing group once a week. I liked to swim and took a day off midweek to visit our caravan and use the swimming pool… Now Norman wants to be by my side at all times so doing things on my own or with my Granddaughter need careful planning and organisation so that someone is with him.
>
> Carol

Ken lives in a very rural village but described how he felt that this did not mean that he could not enjoy an active social life. Ken exhibited real frustrations with his lack of ability to pursue his social life. Ken felt jealousy towards his friends and acquaintances because they had the freedom to pursue their hobbies as and when they felt like it. Ken felt left behind and stuck in his caring role which did not give him the freedom to fulfil his own needs.

> I like the quiet, but there's a lot of people that enjoy the quiet and tranquillity and enjoy an excellent social life. They're down at the gym and meeting people, talking to people, having a laugh, going for a coffee, going out for a meal, you know, a social life!... I talk to other people and they say, 'oh we did this and that' and I think, well aren't you lucky! 'Oh, I'm going for a round of golf this afternoon' – oh, yeah great! I wish I could! I'll just be here.
>
> Ken

Participants valued contact with their friends and families and felt an active and full social life was an integral part of their lives before their caring role. Carol, Susan and Gary described how their social life involved meeting friends and family for social occasions including shopping, cinema and theatre trips, Saturday evening pub trips etc. prior to their caring role. Social lives were often

shared with their care recipient – 'our social life' rather than 'my social life' were phrases used to describe it. With ongoing caring duties and the declining health of the care recipient, this often changed and became a solitary pursuit that the carer would explore without the care recipient.

> Until this point we had a full social life which involved us being together for some activities and separate for others. We went into town together once a week and were together for coffee before going our different ways and meeting up at home later. We went out with friends to our local every Saturday evening and regularly went out for a meal, met up with friends for coffee or lunch every week and had several outings with them in the evening. We were in the happy position of being able to make the most of any opportunities that arose.
>
> Carol
>
> Visits to the theatre or cinema, meals with friends and family were regular items in our diary and we enjoyed the local pub quiz each week. We were always so glad that we would have rich and lovely memories to share as we inevitably became less active.
>
> Susan
>
> Over the past few years we have stopped going to the theatre, don't go out with friends anymore. Friends and even family rarely come to see Julie. Our social life is just about non-existent.
>
> Gary

Harold also felt the loss of friendship as his caring role increased. He suggested that this was due to his own inability to make social interactions due to the rigors of his caring role and that without careful tending, friendships invariably went to seed. Harold obviously felt the loss of social outlet for communicating the frustrations associated with his caring identity as he felt an altruistic impulsion that to communicate these frustrations to his wife would be disloyal and would add to her own burden and feelings of guilt and frustration.

> Due to not getting out I no longer have any friends. When I feel the need to talk to someone I am stuck, because I only have my wife to talk to and I can't put my problems on her and she has enough problems of her own.
>
> Harold

Bob felt the loss of the social aspect of his paid employment which he had to terminate when the demands of his caring role increased. He described light social engagement with work colleagues, jokes and banter which for him, were a valuable source of social recourse. In an attempt to replace these social connections, Bob led a Church group and also became a town councillor however viewed this as an unfulfilling social repast. This was due in part, to the fact that Bob did not drink alcohol and also because his caring demands meant that he had to return home to care for his wife as soon as meetings concluded.

> Yes I did. I enjoyed that, and I mean if you're on a bigger site you might be working on your own but they'd be a group of you. You'd meet for tea break, you'd meet for lunch, there was a lot of banter. And I must admit I miss that. Just, you know, a bit of ribbing. Because I'm a Christian, I've got the beard so they'd say, oh here comes John the Baptist! Or when the thing was going on in Iran it'd be oh here's the Ayatollah! [Laughs] I mean I didn't mind you know, there was one group that used to call me the Preacher. I didn't mind because it was just sheer ribbing, we had other lads who had different nicknames, it was just a way of sort of... socialising really I suppose…And friends... I haven't really got any round here. I mean I've got people that I know in the Church who are a big support and I've got people that I know at the Council because I've become a Town Councillor, so I can feel that I'm doing something, you know. Having said that, they are all acquaintances rather than friends. I don't drink so I don't go out with them for the drink after the meeting has finished, that sort of thing.

> Bob

Holidays were discussed at length by participants and many revealed a great loss when they were unable to pursue them. Holidays described included two week summer breaks but also shorter trips to visit family and friends. For Gary the sale of their caravan was a time of great stress for him. Despite selling a possession, Gary described how he felt he was selling a part of his life, his freedom to explore and the opportunity to socialise with old and new friends through their caravanning trips. The loss of this possession was therefore much greater than it first seemed for him. Gary also described how he and his wife attempted to alter their previous caravan holiday rituals to include coach trips in the UK but this also failed due to his wife's illness. Gary reported that the stress of attempting social interactions such as holidays or visits to restaurants and

cafés became too much for him and so terminated this type of social engagement. The sale of the caravan was therefore the beginning of a distinct shift in Gary's way of life, social experiences and social routine.

> I sold the caravan because she refused to go through the door. She refused to get on a bus when we went on a coach holiday to Scotland, this impacting on people waiting to board in the rain. We stopped going on holidays. I stopped taking Julie to restaurants and cafes.
>
> Gary

Ashleigh recounted a story of going on holiday with her husband whose illness had progressed to him requiring a wheelchair. She described how her husband enjoyed taking responsibility for the planning and organisation of the annual trip when he was well and liked to continue this practice despite his failing health. The couple purposely targeted hotels which catered for disabled individuals, however the arrangements provided were not always satisfactory:

> I remember once we went to Ireland and he'd rung this hotel up and said to them 'can you tell me if you cater for disabled people?', 'oh yes Sir, yes Sir' they said. So he said, 'right well, have you any downstairs rooms, because I'm in a wheelchair?' 'Oh no Sir', they said, 'all rooms are upstairs' so he says, 'well how do I get upstairs to the bedrooms then?' So she says 'there's always plenty of big fellas in the bar Sir!!'So he laughed and thought, they really don't get this, so he said, 'that's fine but how do I get downstairs in the morning then?' She says, 'them big fellas will still be in the bar!!!' [Laughs] and oh, we had a super time in Ireland. The place we eventually stopped at had a reasonable dining room, but they had moved the tables around do he could get his wheelchair in and sat near a window and in another one we stopped at they had double doors into the dining area and they only kept one open, but after the first night those double doors were always open for us… there was always a chair taken away from the tables so he could go straight in. And it's little things like that which make a difference, they don't say anything, they don't make a fuss, but it was very nice.
>
> [Researcher] Did that matter to you, or to him?
>
> Him. Definitely. He didn't, he was lucky that no one ever called him names because he was in a wheelchair, which you do hear about in rough areas. He used to [Laughs] he used to, if people were talking to him they'd say to me, 'does your husband take sugar in his tea?' And I'd say 'well ask him! He's right there!' So as a joke he'd go [interviewee pulls

a face, slack mouthed, eyes rolling, imitating severe mental impairment and laughs]

Ashleigh

For Ashleigh and her husband, it was very important that the hotels they frequented were designed to accommodate customers with disability. The fact that the hotel described above made adjustments so that the couple did not have to request alterations etc. allowed them to pursue their holiday as they did prior to his illness. Ashleigh also revealed a sense of embarrassment which her husband possessed regarding his condition, but chose to make a joke of it rather than confirm any displeasure with the individual during the social interactions that took place. Ashleigh did reveal that her husband was saddened by the lack of social engagement directed towards him solely due to his illness however, despite his sense of humour regarding it earlier and eventually avoided social contacts which could make him feel uncomfortable.

Both Ken and Bob discussed social opportunities for the care recipients. Both felt that it was important that each member of the caring dyad had opportunities for social pursuits away from the other.

Ken felt that Hayley having social intercourse opportunities would provide him with opportunity for the same; to pursue his hobbies, meet with friends himself.

> I think if we could afford for Hayley to have - I'll take away the word carer and replace it with companion. Someone who would be prepared to ring up and say to Hayley, 'we're off to MacArthur Glenn on Friday, do you fancy a trip out with us?' that would be great, I know Hayley would go… and I'd say to myself 'great! I've got x number of hours to myself, what am I going to do?' And I'd go for a walk, go to the gym, I could get that routine in there if it was on a regular basis. But no.

Ken

Susan was concerned that her husband's lack of mobility would affect his opportunities for social interaction and so purchased mobility scooters so that they could both go out together into town. She expressed concern that without this, her husband would become socially isolated which she felt was important to avoid.

> At the moment we can still get about in town on our mobility scooters and I can only hope that he will be able to use his

for a while longer as I feel it is important for him not to get too divorced from the outside world.

Susan

Like Susan's husband, Dorothy recalled the importance of using her motability scooter to maintain social interactions. With her deteriorating health, Dorothy was unable to drive her car but purchased a motability scooter instead. Every day Dorothy would ride down to her local shops, buy her daily groceries and chat to passers-by, her friend the shop assistant and any friends or neighbours she met. This was an important social interaction for Dorothy, maintained through the renegotiated ritual of swapping the car for the scooter.

A number of participants expressed gratitude for their local carer's meeting as an opportunity for social engagement. The carers meetings allowed Gwen, Tracy, Ian and Bob to socialise with people in similar situations to their own. Their caring identity actually developed social opportunities for them and new friendships were made because of their caring roles.

> I started to attend the [local] Carers Group a year ago after a friend in the same position introduced me to the group. It has been very useful, informing me of what help is available as well as a chance to be with other people in the same situation.

> Gwen

> I found out about the Carers drop in group and went along and I have never regretted my decision. It took a lot to walk through the door but the help and support I received was like a breath of fresh air. I have friends I can talk to when times are tough and I began to feel like a person in my own right.

> Tracy

> Just once a month when I go and I talk about the things that matter and we all share experiences and its fantastic

> Ian

> And there's the Carers Group which is a great thing. I can go down there and talk with people who have been there, done that.

> Bob

4.1.4. Emotional Distance

4.1.4.1. Desire to increase emotional distance from the caring identity

Findings identified negative feelings regarding the progression of the participants' own life-course. Expressions of variations of 'my life no longer belongs to me' was common in the data whereby participants felt loss of control, a sense of their life being stalled and of being trapped in their caring role.

A desire to increase emotional distance between themselves and their cared-for so that focus could be redirected to themselves was evident in the findings. Whether this focus was on pursuing their own hobbies or taking care of their own needs, frustration and worries concerning the future were apparent. Participants no longer felt that they had their own life due to the difficulties involved in caring for their family members. Indeed, William felt that he was no longer centre-stage in his own life, but now had to make his life fit around the needs of his wife.

> Everything has totally changed and now everything revolves
> around her, so I really don't have a life of my own anymore

> William

For Tracy and Carol, a certain emotional bitterness was experienced regarding the lack of focus on their own needs. However, Tracy felt isolated and unappreciated, revealed in the tone and choice of words she used to describe it. Alternatively, Carol expressed an importance to remain positive in outlook as a method to maintain her own mental and physical health, although experienced issues when trying to do so.

> I am not allowed to be sick or feel like staying in bed for an
> extra hour or so because I am expected to be at their beck
> and call - no one gives any thought to how I might be feeling
> or if I am having a rough day.

> Tracy

> What can I do to look after my own physical and mental
> health? I try to remain cheerful and my Granddaughter helps
> with this but my husband resents the relationship we have
> and is jealous of the attention I give her.

> Carol

The participants felt that their own health needs were either unimportant, or not as important as the needs of the individual they cared for. They acknowledged that this was the case but felt unable to change things due to their own individual circumstances. The need to increase emotional distance from their caring role for the sake of their own health was apparent in many participants.

4.1.4.1.1. Implications on carers' 'me time'

Although physical health needs were acknowledged by participants to be eclipsed by the needs of their care recipients, many respondents felt the need to increase emotional distance for the sake of their mental health. This often involved attempts to secure periods of 'me-time'; time to pursue personal endeavours away from their caring situation and identity – in effect, to move back towards their old identity for a short period of time, to enjoy the activities they once pursued.

Carol felt the loss of her own free time keenly and expressed her frustration at the caring situation from which she could not attain emotional distance. Carol experienced struggles with the time commitment her caring role involved and wished for greater free time to indulge her personal pleasures; 'time off' from her caring commitments. However, for Carol, there was a need for acknowledgement of the personal cost her caring role had taken, an appreciation of her efforts and the sacrifices she had made for it.

> I feel as if there is no free time for myself and that no one appreciates the efforts I make. Sometimes I barely do cope.

> Carol

Francine's life now revolved around her care recipient and she felt her freedoms dictated by his needs. Her husband wished to maintain control of her and the household, dictating behaviours and ensuring he was involved, despite him being disabled and unable to move from his chair. She shared the need for some acknowledgement in her sacrifices, however desired this acknowledgement specifically from her care recipient.

> 'I don't know what you want to go on about caring for, all you ever do is an hour in the morning and half an hour at night!' that's the way he sees it you see!

[Researcher] Hmmm, I don't think you see it that way though do you?

Well no, because it's a whole way of life really. Everything has to involve him, even as I say, if he doesn't move out of his chair.

Francine

Her remark regarding her husband's incapacitation was said with feeling, which suggested that she felt emotionally controlled, despite possessing a greater physical freedom than him. She too felt frustration that the personal sacrifices she had made had not been appreciated and that her efforts were minimised by her care recipient. Francine wished to increase emotional distance so that her 'whole way of life' did not solely involve her responsibilities as carer.

4.1.4.1.2. Trapped in the caring role

A number of participants expressed feelings of frustration and the sensation of being trapped by their caring role, a role from which there was no escape. Again, participants felt that their mental health needs were eclipsed by their caring identity which manifested in suicide ideation in Gary and William's cases who both care for their wives. For William, the feelings of being trapped in the caring identity centred on his inability to escape the situation, regardless of how he was feeling. His only escape would come with the demise of his wife and felt guilt for wishing it would occur, such was the level of his perceived imprisonment in his caring identity:

Life gets very frustrating at times. You get a feeling of being trapped in a situation you can do nothing about, sometimes you just want to cry or give up but you can't. And yes, you can think suicidal thoughts at times and even wish your partner would die so you can actually have a life… Feeling burnt out but having to keep going.

William

For Gary, his frustration stemmed from the conflicting demands on his time. Until recently he maintained some level of employment but had to terminate this when he started getting telephone calls from his neighbours who told him that his wife had been wandering the streets of their village. Gary's wife would become aggressive and defiant, believing that the time he spent at work was his

way of avoiding his caring duties, adding pressure to his existing feelings of frustration. There was no way out of the caring situation he found himself in and said *"I could have very easily have driven my car into a tree most mornings"*. The identity of carer was not one he chose but one that circumstance forced upon him and was not welcomed, hence his thoughts that only through suicide or serious injury would the situation be resolved and his unwelcome identity of carer be taken away.

This inability to achieve emotional distance from the caring role manifested a desire to escape emotionally, even for short periods of time; however, their caring identity prevented participants from being able to do so. For Tracy and Tim, feelings of being trapped were echoed by an inability to physically escape from their caring identity. Tracy's previous existence had terminated to be replaced by a caring identity from which she was unable to walk away. Added to her feelings of confinement were feelings of frustration and a desire for appreciation by her care recipient and bitterness and resentment that her efforts went unnoticed.

> I felt trapped by 4 walls…I felt like my world had collapsed around my ears. I had no one to talk to anymore…There was no empathy…There are days I could gladly walk away and let him get on with it - he doesn't care about me or my feelings, why should I bother?
>
> Tracy

Tim also felt the need to escape but felt that there was no place he could run to, to get space away from his carer identity. His new identity had taken over all aspects of his life which he accepted with hopeless resignation.

> When things get on top of me there's nowhere I can go to get away. Sometimes I just want to run away.
>
> Tim

4.1.4.1.3. ECE member involvement

The frustration that many of the carers described resulted in the need to increase emotional distance and this had impact on other members of the ECE. For some participants, self-identity as a carer was not an exclusive role. They also had different roles to play in the remainder of their life and some struggled

to balance these conflicting identities. In Karen's case, she had a job, her husband Edward, two children and also Edward's Father to care for. Karen found this difficult and this led to disagreements between herself and her husband. Karen also identified with the conflict her husband had in managing the competing demands of family life with the need for caring for his Father and described it as a *"struggle"*:

> I do find it difficult sometimes, I think, cos it's like having an extra person all the time
>
> [Researcher] How does that make you feel?
>
> Ermm... frustrated sometimes because… I've got a lot on as it is, I'm working full time, I've got 2 kids, you know, we caravan a lot, I've got... I feel like sometimes I don't have time to myself and I think sometimes Edward thinks more about his Dad without even asking me. Like we'd been away for a week and we'd come back on the Monday and he went, 'shall I ring my Dad and see if he wants to come for tea?'… And I say sometimes, its frustration for me and then I get angry with Edward because... he's... always asking his Dad and sometimes I just want to say no...
>
> Karen

Returning from a family holiday, Karen felt the needs of herself and her children were paramount and became angry when Edward suggested that the role of carer also had to be revived immediately on their return. A number of participants expressed the desire to say 'no' to the demands of their caring identity but felt compelled through duty and obligation to redesign their self-identity to include their caring responsibilities.

> It took us a long time to understand it… Edward said 'I'm like a tree. I've got all these branches and everybody wants a bit of my branch', he said, 'I'm trying my best to please everybody' and he said 'I feel like I'm pleasing one person I'm upsetting another person… I just feel like I'm torn…I want to go and spend time with my kids and do stuff but I also need to make sure my Dad's alright, but I also need to make sure Karen's alright…
>
> Karen

As a tree, Edward felt that his self-identity was split into branches, from carer, to husband to Father. He felt conflicted by the many roles his identity had to include and guilt if one role took a bigger branch than another, resulting in his

multiple selves being out of balance and affecting his own wellbeing. His actual desires and own needs were not considered in his analogy and it was clear that he felt pressure to share the branches of his tree fairly.

Edward explicitly detailed the competing demands he felt bound by when he and his wife Karen initially moved in with his Father to help look after him and it became apparent that co-residing was placing a strain on the remainder of his family. This was exacerbated by the multi-generational structure of the family living under one roof, increasing tensions in areas other than caring, such as child-rearing.

> Living with elderly parents!... and they have totally different opinions to what you have…My Dad used to snap at Karen… he was starting to snap at Karen for way she was doing things with the boys and... You know – 'that's not the way I'd have done it', so, of course she starts to get a bit 'right I'm not having this anymore'. It came to a point where something was gonna happen, I'd regret what we were gonna say...
>
> Edward

Tensions were increased whilst the family co-resided and were forced to balance their new roles and identities with those they possessed prior to Robert becoming ill. Their new carer identities were not being readily accepted by his wife and yet Edward still felt compelled to pursue them.

The decision to move back home was not Edward's but that of his wife Karen. Although he described the reasons for the return home in interview as the emotional tensions of co-residing and lack of emotional space in the caring identity, Edward felt unable to reveal this to his Father and so blamed pressures of work and commuting for their imminent departure when he informed his Father. Edward also did not reveal that it was Karen's decision to return home, fearing that this too would cause tension in the family. Edward was unwilling to vocalise the increasing emotional pressures their living arrangement were placing on the remainder of his family, but felt that as a hard-working man himself, his Father would understand and accept work pressures as a valid reason for moving back home. In this way, Edward maintained the emotional closeness of their relationship, forged under very difficult circumstances through the telling of some half-truths. However, was unable to articulate their decision without upsetting his Father and so looked to his wife to explain the decision in

a way that would not upset him. By working together, emotional closeness was maintained by the ECE, despite the imminent increase in geographical distance between them.

> For 6 weeks we lived with my Dad, we went back to work and about the 5th week, I said to my Dad... and I did it totally the wrong way... I said to him Dad, [unintelligible] we're off home, instead of being a bit - tiptoe about it. So my Dad kind of made a fuss about that... He was like, 'uhhh just upping and leaving me', I said no it's not like that... so then I went to Karen.. she said, 'look Robert, we're not saying about upping sticks tonight and going, I'm just letting you know that we're thinking about starting to move back.. back you know, to our house... because you know, we need our... time to ourselves also'. And quite rightly so. My Dad needed to start being independent because if he came to rely on us…it would have been more and more difficult to leave, and it would have put a strain on our relationship.
>
> [Researcher] How did you feel? ... Did you feel guilty about leaving him?
>
> I did feel guilty to start with I suppose. But, I'm quite a level-headed person and I know we couldn't have stayed there forever and you have to make the step... it's tough love, you've got to... got to do it you know? But my Dad also knew that we had to work. My Dad's grafted all his life so he knows that people have to get up on a morning and go to work and if somebody... you know, relies on you, then for them to be a burden like that... my Dad thinks [that] is not acceptable.
>
> Edward

Emily felt a similar sense of competing demands providing care for her Mother in law Liz and expressed her frustrations in caring due to the involvement of her entire family – in particular her young sons who became bored when visiting their Grandmother. Emily also expressed her frustration at feelings of guilt and pressure from Liz, which has consequences on the entire family, such as their ability to plan a summer holiday. Unlike for Edward and Karen, Liz purposely added feelings of guilt to her ECE in an attempt to trap them in the caring identity. Liz reportedly resented Emily and the family going on holiday because it left her alone for the duration. In response, Emily resented the pressure Liz added to her life by making them feel guilty for leaving her.

> I suppose it's so tying. Especially for my boys as well, because like they have to go, and they like going to Liz's but

> then they're bored because there's nothing to do. It's like
> when we went on holiday it was awful because we'd ring her
> and she'd be like when are you coming home? And she
> knew when we were coming home, but it made us feel awful.
> Putting pressure on. I have seen a change in that sort of
> thing. It's like the 'old person guilt' isn't it. She lays it on,
> makes us feel guilty.

Emily

For Emily, the idea of a summer holiday was to temporarily halt her caring existence and return to her previous life and roles which did not involve caring. A vacation was a method for securing temporary physical and emotional distance from being a carer and Emily felt angry that this was denied by her care recipient.

Although many participants wished to increase the emotional distance they experienced between their self-identity and their caring role, others wished to maintain the status-quo. Catherine received formal and informal care from paid carers and neighbours as her family were geographically spread across Europe. Catherine wished to maintain the level of emotional distance she currently had from her children in an altruistic attempt to ensure her children lived their own lives to the full. In contrast to participants such as William, Tracy and Emily, Catherine was aware of the potential to trap her ECE in the caring role and wished to avoid it. To do this, she communicated her wishes to keep her ECE at arms-length emotionally, readily accepting and articulating that their existing identities should not be altered to include caring.

> I'm a great believer in that... life is for the living. People are
> living their lives to the full, doing a good job, doing a job that
> their family depends on to live, that is more important than
> them coming up here for a night or two, to me. They accept
> this. I've talked them into it really.

Catherine

Ian was elderly, residing with his wife and possessed dual identities of both carer and cared for. His wife was ill and infirm and he provided basic care for her. However, his own health was also deteriorating and so assistance was provided by their adult children to form a coherent ECE. Ian wanted to increase emotional distance from the remainder of their ECE – namely their adult children. He viewed himself as lucky that their adult children lived close by, but

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also acknowledged that at times, it would be easier if they lived further away as they would be less involved in the minutiae of his and his wife's life. Ian balanced his feelings of frustration with the children's interference with the need to keep them onside for potential use in the future as he and his wife became more infirm. He utilised a number of methods to maintain emotional distance from his children, including an attempt to maintain independence and autonomous decision making whilst being sympathetic and understanding that the motivations of their adult children were benevolent. Ian appreciated that his children wanted to help and so allowed this to some extent, implying that he did not wish to isolate them for fear of the future, when their input may actually be required:

> [Researcher] Your family sound lovely and caring and very involved. Do you ever feel that they are involved a little too much?
>
> I think we do at times. I know Pam does. Sometimes in the beginning they did overstep the mark a bit. George used to come round and say, right, you need different chairs and so we said, well no, we like these ones.
>
> [Researcher] So did you put your foot down?
>
> Well, we had a bit of a job actually. But the only bossy one really is Shirley, she cares wonderfully for us. But we do have to put our foot down sometimes, like when one of us has come out of hospital and she says she's coming to stay. We don't need her to so we try to tell her not to bother.
>
> [Researcher] Does it work? Does she stay with you?
>
> Well yes, because we don't want to upset her and really, she is only being kind…there is this feeling of, you know, we can do it. We do at times feel, I wish they'd leave us alone, I wish we could just get on with it. But we know as we get older… It's a strange thing actually because in some families where there is some [geographical] distance, you don't have a problem because you don't have that ... independence problem because they're not close enough to interfere too much, on the other hand, when you do have them close to hand they do tend to interfere, I don't like to use that word, but interfere in a nice way to do things… Pam, who is a much stronger character than me, she's found it very difficult to give up her independence, and still does.
>
> Ian

Despite vocalising that he and his wife put their foot down, Ian's ECE did not respect the emotional distance Ian attempted to induce and their wishes and decisions were overridden by the ECE and in particular, their eldest daughter and eldest son. Ian elaborated with a tale of his son insisting they needed new chairs which allowed them to stand with greater ease. Ian and his wife vocalised their dissent with the change to little effect and their son purchased the chairs (using his parent's money). When asked if the chairs had been useful, Ian confided that they did not use them at all, had kept the old ones and only used the new ones when their son came to visit. This minor deception allowed Ian and his wife to maintain control in what chairs they used, allowed them to feel autonomous in their decision-making but also kept the peace within the ECE, keeping emotional distance between them and their family at an optimum.

Other participants also recalled acts of small covert deception in an effort to ensure optimum emotional distance between themselves and others. Participants also speculated on whether some of these acts of deception were actually designed to be discovered in an attempt to secure attention from the ECE.

Katie experienced conflict with her Mother in law Ann, and tried to increase emotional distance between them. A running source of tension between the two was the washing and showering of Ann. Ann attempted to deceive Katie by insisting she had showered, however Katie used notes from the formal carers to confirm that this was not the case. Katie felt within her rights to insist that Ann showered and negated her attempts at deception. The motivating factors for this deception were not really understood or sought by Katie, other than suggesting it may stem from embarrassment of being naked in front of virtual strangers. Katie was unwilling to attempt to understand the reasons behind the deception or tackle them to ease the tension. Instead she focused more on winning the argument by ensuring Ann was showered daily. Katie pursued this to the extent of cataloguing Ann's excuses and tackling each one so that she ran out of reasons not to shower, for example purchasing shower caps so that she didn't wet her hair.

> She says oh I have a good strip wash, but the good company
> we use ring and text me all the time and it's like, they say she
> refuses to shower and look through the other company's

notes and tell me she hasn't had a shower for 5 days. And she'll tell them oh I had a shower this morning and they'll be like, no you didn't… When I check her flannels they're bone dry… She says she doesn't want to get her hair wet because she goes to the hairdressers every Saturday I tell her but we've put the level down so it won't touch her hair, and we've got you shower caps and things so there is no need not to… When... at first they were going in and waking her up, so that was good because they know she hasn't had a shower or anything like that but now she gets up early, so she's dressed when they turn up to outfox them and when they come on a night she's already in her nightie, so she knows exactly what she's doing.

Katie

Ann strived to maintain independence and autonomy through avoiding the shower. Her reasons for wishing to do so are not known or understood, however Ann felt strongly that she was able and entitled to make the decision herself as to how often she takes a shower. Ann's behaviour however, demonstrated that she was not willing to communicate this to her ECE explicitly. Instead, she told untruths and altered her routine so that her aim was achieved, but not known about by her ECE (but was later uncovered by Katie). Ann may have taken this approach to cause least disruption and tension within the ECE whilst still making the decision to not shower autonomously, in a similar way that Ian hid the old chairs when his son came to visit. However, Ann may also have acted this way, expecting her deceptions to be revealed in an attempt to illicit further emotional contact with her ECE, although the deception resulted in only anger from Katie.

Katie also expressed mistrust and annoyance regarding the physical falls her Mother in law experienced and suspected that the falls were either imagined or planned to secure emotional attachment and attention from her ECE.

A couple of times she said she'd fallen and it was questionable whether she had, or whether she had actually done it on purpose to get attention… If she was out and about on her own she'd be out pottering around and she'd be fine but if you're with her she staggers, trips and things.

Katie

The possibility of the falls being non-accidental was never considered by John, Katie's husband, nor had Katie ever discussed her suspicions with him or any

other member of the ECE. John was content to assume that her falls were due to her medical problems, due to "*getting old and unsteady*" and did not analyse them the way Katie did.

Potentially, Ann sought to increase emotional closeness with her ECE and found that her ECE were more attentive if they thought she was at physical risk, either through levels of cleanliness or through falls. Katie implied that she was aware of the attempted manipulation and resented it and was also aware of Ann making autonomous decisions and resented that too.

4.1.4.2. Desire to decrease emotional distance from the caring identity

For some participants there was a desire to decrease emotional distance between themselves and their caring role. This was attempted through increased contact between the carer and cared for, or through increased emotional connection with ECE members or even other individuals outside of the ECE. Participants reported feeling loneliness and isolation in their new caring identity and even reported using possessions as tools for reducing emotional distance.

In some ECE's, the members felt the need for increased emotional proximity, as a protective barrier against emotional upset. In Catherine's case, (whose family live some distance away and is cared for by formal carers and her neighbour) her motivation for daily living was the weekly visits she paid to her husband who resides in a care home. It was of vital importance to her that she put on her makeup and maintained a cheery demeanour when visiting him in an effort to minimise his distress. Catherine deliberated her motivations when her husband died as her existence was centred on minimising emotional distance between herself, him and their old life together. It was of vital importance to Catherine to maintain emotional proximity to her former life, through maintaining her appearance (so she looked how she used to look) and maintaining the house (so it was in the same state of repair as it was before her husband moved into the care home).

> [Researcher] Do you think any of your children could have, or could do in future, more for you?
>
> Frankly I don't know how long... we are assuming of course, but we don't know whether it's going to be Roger or I first

past the finishing post! [Laughs] but if it were me and I were left here, I don't... I can't visualise how long I would want that to be. It would be like being without the motivation of looking after Roger. He's my motivation, is Roger. To keep him happy when I see him and keep the house running, so that if he came to it, it would be like he left it. That's totally my motivation now... Lucy was upset this time, when she saw her Dad, she came home and had a weep. A lot more of him had gone and I said, 'I haven't done that yet'. Because I think if I did I'd never stop, but the time will come when I will obviously. But mentally I've got to keep this going. When I go and see him I'm always cheerful, I keep myself looking how he expects me to look, I hold his hand, give him a kiss... He doesn't initiate much, if any conversation now, so I have to keep it going, and they'll be a response every now and then. And I'll take him those photographs of the children to show him… My motivation is Roger, as I say, I can't anticipate when that motivation isn't there anymore.

Catherine

Catherine was determined to remain emotionally strong for the sake of her husband and wider family. She desperately held on to aspects of their previous life together and attempted to continue them through maintenance of her own physical appearance (makeup), through physical affection (kisses and hand-holding) and through possessions to stir memories (photographs). Her motivation in life was to keep the emotional distance between herself, her husband and their former life together as small as possible, so that her identity remained unchanged as far as possible.

4.1.4.2.1. Communication and ECE member roles

Feelings of loneliness and isolation were often identified by participants and expressed via a desire to decrease emotional distance between themselves and the remainder of the ECE. Fred cared for his wife alone and expressed feelings of isolation in his caring identity. He felt that his family did not assist or support him, however recognised some value in the resulting autonomous decision making:

When I look back they didn't do anything to help, except that they went along with the decisions I made. So by not getting involved they helped me, by going along with everything. They took the easy way out. It was very lonely.

Although quite bitter that his family did not get more involved with the care of his wife, Fred identified that this emotional distance allowed him the freedom to make decisions affecting his and his wife's lives. There was no interfering or overstepping of boundaries, such as those experienced by Ian but instead there was loneliness and a sense of sole responsibility for the care of his wife which he found very isolating. Fred had limited contact with his family and had never been emotionally close, even when his wife was well. Fred's expectations of a change in emotional distance – an expectation that the distance would decrease because of his wife's illness, were unmet which caused consternation and feelings of frustration with his family – "*they took the easy way out"* and left him to cope alone.

Carol, Susan, Neil and Tracy also expressed feelings of isolation and loneliness in their caring roles. All expressed a desire to reduce emotional distance through increased social interaction with other members of their ECE, or even their care recipient. A common theme identified through participants was the absence of communication opportunities, which linked to their feelings of social distance also. Differences did exist between participants however. Carol felt a desperate need for support, despite fearing that the revelation of the severity of her situation and feelings in her caring role would put a strain on a friendship.

> I have a friend who is very close, both emotionally and physically and I talk to her a lot, although I feel I cannot burden her with all my angst.

> Carol

For Susan, her desire to communicate, to actively share her life with a companion was tantamount. Her husband, who once provided this was no longer able to and Susan desired a replacement companion to halt her feelings of loneliness and isolation.

> He is still keen to contribute to our relationship…often asks me "what can I do to help". My unspoken reply is "how I wish you could"…There are many things which I cannot easily do... One of these is simply to talk about the situation…sometimes I would like to just talk to someone, laugh about the funny aspects of the situation, have someone understand the heartache and loneliness I feel at

> not being able to share things (TV programmes, political
> issues, world events, local news). It's not that I want advice
> on how to cope with it - it's more a case of having someone
> to simply understand that we've always shared these things
> and I miss that sharing.
>
> Susan

Susan also revealed a sense of duty and obligation in her caring role, using language suggestive of defined responsibilities in which she was isolated from others:

> The family are very good and I can discuss things with them,
> but ultimately the buck stops with me and sometimes it can
> be a little frightening.
>
> Susan

Although able to discuss her situation with the ECE, Susan felt an emphatic, sole responsibility for decision-making – a role she never had prior to her husband becoming ill. For her, self-identity as a carer also meant lead decision-maker which did not sit comfortably with her.

Involvement of the wider ECE can be unwelcome, such as in Ian's case, wanted - but absent in Fred's case, or for some, can result in anger and the permanent breakdown of relationships within the ECE if expectations within the group are not met.

Neil felt anger that other members in his ECE were not more involved in caring for his Mother. For Neil, the priority should have been visiting his Mother (which was certainly his main priority) which was a view not shared by his sister. For her, other priorities existed which trumped visits to their Mother which caused irreconcilable differences between the two.

> I hope to share this [caring role] with my sister but her often
> repeated mantra to both me and our Mother is "I only have
> one day off and I want to spend it with my husband".
> Eventually managing to visit for an hour every six weeks or
> so - fair enough, you are not alone if you think that is
> adequate but I cannot understand it personally.
>
> Neil

Neil explained that his sister became jealous of the time he spent with his Mother which culminated in a big family argument - Neil and his sister never

spoke again as she died some time later. He revealed that his sister blamed him for the emotional distance between herself and her Mother and even stated that it was this that made her ill. Neil disclosed the ECE tensions dispassionately, with no regret or self-blame regarding the death of his sister. For Neil, lack of activity in caring within the ECE was so serious a crime as to never be forgiven.

For other participants, involvement of the ECE and buy-in by all members into the carer identity was crucial. For Robert, the existence of the ECE was instrumental in his physical and mental recovery from the car accident. He described situations where emotional proximity was a priority for all members of his ECE.

> Oohhh, without them [the ECE members]... without a doubt
> I'd never have got through what I've got through… Without
> them I wouldn't... well, I wouldn't have survived no doubt.
> Well, I might not have survived it even physically, but
> mentally I would just have, you know chucked the towel in
> you know, because I... I just couldn't see a reason for living
> really, at that time.
>
> Robert

When Robert returned to the UK after his accident, Edward (his son) and Karen (his daughter in law) moved into the family home to care for him. The group have all discussed the point in which they decided to return home and all see the incident in slightly different terms. Robert felt angry and abandoned at the time, but on reflection felt that these emotions were selfish – he did not wish to increase the emotional distance between himself and the ECE and felt that emotional proximity could only be maintained through co-residence.

> [Researcher] Do you ever feel that Ian and Karen could have
> done more for you, either back then or now or?
>
> I did at the... I did when they left. I did say, 'what are you
> leaving me for'. I never realised it was just a selfish...
> because at the time I was struggling... it gets, well I won't say
> it gets easier, but you know what I mean… [You are told] you
> never forget but it does get easier. So, you ask the question,
> when's this easiness going to start?
>
> Robert

Robert's ECE took different roles to maintain emotional closeness. Edward felt that Karen took the lead in this role because of her natural personality, but also because of her gender. Edward admitted that he struggled in this area and encouraged Karen to take the lead.

> I think he's quite happy, my Dad. But you never really get anything out of him so I don't know really. He'll open up to Karen more than me, but only because she pushes him…She'll... He'll come round and she'll be like 'you alright Robert?' and he'll be like 'ohh, welllll, I...' so Karen will be like, 'come on, what's up with you?, come on!' whereas if I see him and he's like 'well, imm okk' I'll be like 'oh right, OK then'. And I'd just leave it at that really…Whereas Karen, because women are totally different... One morning we got up and my Dad was like 'ohhhh, I can't cope on my own' and just broke down in front of me and I was like??... Karen had to hug him and sort him out, you know, 'come on Robert sit down and talk to me' and all that sort of thing.

> Edward

Robert and his ECE all accepted the importance of emotional closeness between them as key to successful caring. Each member took a role so that the carer identity was shared throughout the group. Karen took the role of communicator and comforter whereas Edward organised practicalities and scheduled visits. Robert's younger son Chris (although residing over 200 miles away) took the role of 'checker' - telephoning his Father every day to assess his well-being and report back to the other ECE members.

In contrast, Jayne felt responsibility and control in her caring duties and actively discouraged the wider ECE members from becoming too involved. Although she admitted to being a stubborn and controlling person, Jayne was able to identify that the lack of input from other members was in direct response to her, not fear of the caring identity. Jayne's self-identity was completely absorbed by her caring role and she did not wish to change this, or share the identity with other ECE members.

> To be honest like, when we were talking about [sister], my daughter said 'Mother even if she wanted to you'd probably refuse; you wouldn't let her!'

> [Researcher] And would you?

> Probably not! {Laughs} Because it is really difficult to let go of something that you're running and very smoothly, to let someone else come in and start doing bits of it.
>
> Jayne

Jayne was very conscious of her role and responsibilities as eldest daughter in the family. She had made a promise to her Father that she would care for her Mother when he was deceased and this promise defined her self-identity to such an extent that she did not want involvement from others which could detract from this and actively encouraged emotional distance with the rest of the ECE. Jayne also needed emotional distance to exist so that it could be used as a bolster to her self-identity as sole carer and be used as a tool to elicit feelings of guilt from the other ECE members. Jayne admitted to denying other ECE members' roles in caring for her Mother but also conversely admitted that she made other members feel guilty for their lack of involvement.

4.1.4.2.2. Possessions and rituals as tools for minimising emotional distance

Sharing the carer identity throughout the ECE was one technique employed by participants to manage caring for a family member and ensure emotional distance was kept to a minimum, but could only be successful in a relatively harmonious ECE with a substantial number of members. For other participants, this approach was not possible and so alternative techniques for minimising emotional distance were sought.

Some participants and their ECE members attempted to minimise emotional distance by attempting to do things they used to do – such as cooking and cleaning, because these activities were linked to their previous identity and role within the family.

Emotional connections could also be embodied by an object or possession, providing closeness and value much greater than basic monetary worth. Possessions and objects were also used as evidence of coping or as an aid to memory, a keepsake or even to minimise emotional upset. In this way, objects and possessions were used as tools for reinforcing self-identity and altering

emotional distance - hence, the loss of a possession sometimes had a greater emotional impact than expected on participants.

Bob expressed a deep sadness from the sale of the family's caravan. To him, the caravan was a symbol of freedom, independence and a conduit for social interaction. The sale of the caravan was to him, a great step in losing his former self identity and replacing it with his carer identity. Bob's emotional attachment to the caravan was the reason why it had not yet been sold, despite the fact that it was no longer used.

> We do miss it, but there it is. It was freedom, to go where we wanted to go, when we wanted it. That's probably why we haven't sold it. We keep saying, but we never do anything seriously about selling it.
>
> Bob

Ian reflected that his wife also felt emotional attachment to the objects and possessions used in the rituals of her former life, prior to becoming ill. The provision of a Christmas hamper for each family member was a very important ritual for his wife Pam, linked to her self-identity of wife, Mother and provider of sustenance for her family. Because of her failing health, Pam was unable to produce a Christmas hamper last year, but saw great importance in producing a Christmas pudding and a number of small components of the previous hampers. The moderation of this ritual was essential for Pam's identity and was acknowledged by other members of the ECE.

> [Researcher] is it important that Pam cooks and bakes?
>
> Oh yes! Absolutely! The kitchen is her domain, always has been and she's done them a hamper each every Christmas, made green tomato chutney, apple chutney, piccalilli, red cabbage, Christmas cakes, shortbread, all sorts. She can't this year though. She's going to just make some shortbread and the Christmas puddings because they all like them. It will make her sad, not being able to do it all.
>
> Ian

Although the ritual of making a Christmas hamper was moderated, Pam was still able to derive some pleasure from it, despite also experiencing regret over the moderation. Pam was able to maintain a link with her previous identity and because of this, ancillary objects took on greater emotional meaning which

helped bridge the gap between previous identity and new identity. Ian recalled the importance of the baking ritual for Pam, although acknowledged that this would have to be moderated. However, a key possession for Pam was the old and chipped mixing bowl she had always used for her baking – an item that she could no longer hold without the assistance of her daughter. It was important for Pam to continue the ritual, indirectly using her familiar possessions to maintain an emotional link with her former identity.

> Mandy [daughter] normally comes and helps her with it a bit. She likes to do it with her Mum. Pam's got a big old mixing bowl which she can't really hold anymore, but she'll get everything prepared.

> Ian

For Robert, feelings of loneliness and isolation, particularly at night time, were difficult to manage and possessions were a mechanism to reduce emotional distance, emphasised by the emotional value he had placed on them. Robert was reluctant to use the TV because of the emotional value he had placed on it as a link to his previous life when his wife Patricia was alive. Robert also knew that he must start to use items such as the TV as a method for dealing with his grief and tackling his loneliness by taking an interest in other things – effectively minimising emotional distance between himself and his previous identity.

> Well, yeah, you do. You do feel lonely I must admit… I still don't watch... well I won't go in there and switch the telly on. I go on the computer and then...very rare do I switch the telly on and that's what I need to start doing…Since the accident the one in the front room has never been on…one in the bedroom - I've even pulled the plug now, it's never been on. So, and the other one in the back room is hardly on...I just don't know why. I just don't seem to get... interested in things... I realise that I'm going to have to start doing that - watching telly.

> Robert

Robert's younger son Chris also valued the use of possessions in minimising emotional distance and purchased his Father a radio for this very reason. He felt that the sound of human voices on channels such as the world service would provide a link to his previous existence prior to becoming ill, allow him to

feel a connection with the outside world and hence minimise his loneliness at night.

The purchasing of new possessions to tackle loneliness and isolation had a certain level of success for Robert, and the redesign of old rituals helped him to feel less isolated. Chris used to telephone his Mother each day on the way to work and since her death, has transferred this routine to his Father. Chris also disclosed that he and his Father exchange letters as a way of minimising emotional distance. Chris also implied that the emotionally fraught topic of his Mother's death was discussed only via letter and that no face to face conversation regarding this topic had yet taken place for fear of one upsetting the other:

> He err, he wrote me a letter a while ago and he did say in there that he looks forward to my call in the morning.
>
> [Researcher] What gets said in a letter that doesn't get said elsewhere?
>
> I don't know… suppose if I think he's feeling a bit down.
>
> Chris

The amended ritual of telephoning his Father and the new ritual of letter writing has assisted the ECE in maintaining emotional proximity to one another, despite the grief felt by all over the loss of Patricia and the geographical distance between the two.

The ECE members worked together to minimise emotional distance for Robert, however difficult topics (such as Patricia's death) were never discussed face to face for fear of upset, of undoing the work already done to ensure emotional proximity. This was shared by Diane, Robert's sister-in-law.

Diane acknowledged that Robert remained lonely, particularly at night. Robert spoke with her frequently because Robert was afraid of the emotional burden or upset he would cause his other family members if he were to confide in them, namely his adult children.

> I found that he could possibly talk to me where he couldn't with his own direct family.
>
> [Researcher] Why's that do you think?

He was afraid to upset them. And I knew, he would tell me. But if it was anything - he doesn't know this! But if it was anything I felt they'd be better knowing I would tell Karen.

Diane

Diane understood Robert's need for some emotional distance between himself and his children as a method for ensuring the harmony of the ECE and through genuine concern for their emotional wellbeing. Interestingly however, Diane confirmed she would break Robert's confidence if she felt he had revealed information she felt the other members should be aware of. The role of 'double agent' was acceptable to Diane who respected Robert's need for some emotional distance between himself and his ECE up to a point, however the need to break of Robert's confidences and potentially disrupt the harmony of the ECE was worth it in certain circumstances.

There are a number of emotional attachments to possessions seen in the data – for example, Catherine's family car. Catherine's car was owned by her husband who now resides in full time residential care. The car was old but held many happy memories for Catherine of trips out when the children were young, evenings out with her husband and even road trip holidays. She felt very strongly that the car should remain in the family and be used by the next generation. The emotional value of the car was very high and, although not now used, was almost regarded as a member of the family. Its emotional link to previous identity and lifestyle were invaluable, despite being worth little in monetary terms. The thought of the car being sold and used outside of the family was anathema to Catherine, particularly as the rehoming of the car had yet to be discussed with her husband. Catherine and her ECE discussed the subject as a group and came to a decision together:

> He [her husband] doesn't know, he's never raised the question of the car, and I've never mentioned it… Our older daughter has taken it to her children who live in London to share it… Her son lives there so if they want to get out of the town and have a day out, that car has gone into the family. Grace and her husband had it re-serviced, spent a lot of money at the Garage with new this and that. So it's still in the family. But funnily enough, Roger has not mentioned it once, and I will never! Because he would start asking questions!...When we talked to the family, because Lucy… said, oh, you're in the AA, well, Dads not going to drive

again. He may say yes if you ask him if he's going to drive again, but I'm telling you, he's not going to drive again… And they talked about themselves, obviously they were going to handle the finance themselves, and made this decision... So it's still in the family.

Catherine

Catherine had invested great emotion into the car as a way to remember happier times in her former identity. As a practical person, she realised that the car could be put to better use and so allowed the family to use it. By doing this rather than selling it, Catherine was able to keep a tenuous emotional link with those times, minimising the emotional distance between her present situation and her previous life prior to her husband becoming ill. Catherine spoke with pride that her family had spent a lot of money in reconditioning the car and were enjoying building their own memories by utilising it. Catherine even compared some stories she had been told by her family (such as them travelling to the beach for a day trip) to the trips to the beach herself and her husband used to also take in the car when the children were young. This maintained an emotional link with Catherine's previous identity, despite not actually possessing the car herself.

Francine expressed a desire to secure emotional proximity for her husband to his previous life, (before he became ill). This was done by moderating their previous routines to allow for his disabilities, despite her own non-interest in the pastimes. Prior to his illness, Francine's husband was a farmer and lived as self-sufficiently as possible and always grew his own vegetables, produced his own eggs and meat and expected Francine to cook every meal from scratch. Although these demands on Francine have now lessened, she still felt it was her responsibility to retain aspects of this former life for as long as possible as a key to preserving her husband's happiness and peace of mind. Renegotiating old routines to allow the involvement of her husband was not the simplest choice for Francine to take. She freely admitted that if it was up to her, she would buy all her vegetables from the supermarket. Having always had her husband as the main decision maker, Francine allowed the change in routine to include the continuation of vegetable gardening so that he maintained a link to his previous identity, knowing that its loss would cause him distress. His need to keep his hand in was accepted by Francine and she compromised her

behaviours to include care of the vegetable garden. Francine saw it as part of her role as wife and carer to maintain her husband's interest in other things. Although now physically unable to carry out the more manual tasks of gardening, Francine has moderated their behaviours so that he can still be involved, hold an interest and feel some sense of accomplishment. She does this for the benefit of her husband, despite not being keen herself on vegetable gardening. The renegotiated ritual therefore provided emotional proximity to her husband's former identity, but also provided a means of achieving a level of psychological distance for her husband; keeping his mind active and engaged in the manual task of vegetable gardening.

> And in the last few years he's got worse and worse, in fact he's just not that interested. Not interested in anything really apart from the garden. So, part of my job as I see it is keeping his interest going, so I mean vegetable gardening is not my thing at all, but I've kept it going for him. He has to sow the seeds and transplant them and that sort of thing and then I deal with it in the garden and he tells me what to do and what to spray - he enjoys that.
>
> [Researcher] So he's still very much directing...
>
> He's directing me and what I do, but I've chosen to do that because I don't want him to be sitting in a chair miserable. I want him to be interested. He's taken loads of cuttings and he's bringing them all on. I have to bring the compost in in a bucket so he can do it in here, but he takes the cuttings. It is very important for him to do that. It's a remnant of the things he used to do, that he can still do. He looks after them on the windowsill, so in his mind he's keeping his hand in. And I'm happy to do it for him, most of the time! [Laughs]
>
> Francine

Francine used the renegotiation of old rituals and practices to ensure emotional proximity for her husband to his former identity in a similar way that Ian's daughter now held the mixing bowl whilst assisting her Mother to bake. These compromises to old rituals were very important to both carer and cared for and resulted in minimising distance in two different ways; by helping to ensure cohesion and harmony in the ECE by creating new activities both parties did together and thereby creating emotional proximity between ECE members and

also by providing links to former identities, allowing emotional proximity to former self-identities.

Dorothy now resides full time in a nursing home but continues rituals that she upheld prior to her admission to the care home. Throughout interview Dorothy expounded the values of emotional proximity through social engagement. Family and friends, parties and celebrations were very important to Dorothy as a means for maintaining her self-identity, enlisting the help of her ECE to ensure her participation in the care home's Halloween party:

> I can't be anything other than how I am. I might be a bit
> eccentric at times - I've got my witch costume and my
> brother's just brought a nose for me! I wanted one with a wart
> so Rob [son], when he comes back, I'm going to ask him to
> get me some warts from the joke shop to stick on my face. I
> love Halloween and we are having a party.

> Dorothy

Dorothy enjoyed celebrating Halloween and still expected to take part in it, despite her ailing health and change in circumstances. The continuation of old rituals, with certain alterations was acceptable for Dorothy – she did not mind asking her son to buy her costume rather than choosing it herself as she did previously as long as she was still actively engaged in the celebration itself.

Not all of the rituals that were important to Dorothy had been upheld however; Dorothy felt an emotional loss when she realised she was physically unable to purchase Christmas gifts for her loved ones and instead had to give them gift cards. For many years prior to her move into the nursing home she had invested emotional value in saving the money to purchase gifts for each individual, took pride in choosing individual gifts that she anticipated would bring great joy to each, and enjoyed seeing her family open them on Christmas day. The anonymity of giving gift cards she felt, detracted from the emotional closeness that gift giving gave her and her family.

> How can I explain... this Christmas I'm not buying presents?
> Now, I got the joy from buying presents, I had the money, I
> always saved, saved in a didlum. Now this year I'm having to
> get them gift cards, you know vouchers. So I feel a bit sad
> there. I liked doing what I used to do, shopping for them. And
> doing it this way, just writing on a card something, it isn't a

Christmas present, to me. But I know that I can't do it now
so, I suppose I do feel sad. Very sad, yes.

Dorothy

Dorothy also felt a great emotional attachment to her previous house, however had to leave it due to her failing health. The decision was taken for her to take up full time residence in a care home as a group decision between all ECE members, however Dorothy obviously still felt the loss very keenly, despite it being some years ago.

It was their idea. Between them, they decided about me coming in, well. When I was ill last year they wanted me to come in a home and I said no, I wouldn't come in a home. If I was going to be ill and anything happen I'd rather be in my bungalow, because I loved my bungalow. [Interviewee starts crying] they sat and talked to me because I was having falls and it's alright having neighbours, family and the carers coming in but they couldn't guarantee when I was going to have a fall.

Dorothy

Dorothy felt an emotional bond with her old home and expressed her desire to end her days there. She understood that for her safety she would have to leave the house (which happened a number of years ago) and yet was still reduced to tears when considering her emotional loss. She had resided in her bungalow for many years and was well-known and well-liked in the neighbourhood. She was one of a number of widows on the street who socialised and looked out for each other, a member of the old-school fisherman's wives who had moved to the area when the Hull docks had closed down in the 1980's. Her identity was inextricably linked to her home, her bungalow was part of who she was – independent, autonomous and liked by her peers. Therefore, the loss of the bungalow was also loss of her previous identity.

Dorothy used possessions as a method for decreasing emotional distance in other ways. Dorothy recalled her mobility scooters as a method for independence but also as a tool for self-identity. Dorothy's son Mike bought her a joke number plate for the scooter so that the local residents could identify her. The number plate meant so much to her that she still keeps it in her room in the care home.

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> Oh yes, the independence! …I loved them, really did! I had 4 scooters in the end, always red! I love red. On the big one Mike bought me this number plate, everybody knew me. Now I've got it on my seat in here, my electric thing, I've got it on the back of there – "Dorothy's Wheels!" Yeah! I used to get my carer, she used to get the scooter out and put it so I could get on it. Once I was on it I never got off until I came back. And then somebody else, like a neighbour or whoever was around would come and help me get off.

> Dorothy

Dorothy's self-identity and identity to others was embodied by her prized possession – the big red scooter with her own name on the number-plate. Even when she was not well enough to really use it (having to stay on it until she got home and then rely on a neighbour seeing her and being willing to help her off it) she maintained the ritual of using it, getting out and being seen by her neighbours, going to the local shopping mall and maintaining the rituals she used to participate in. This was extremely important to Dorothy to the extent that, although these rituals had now ceased due to her ill health and change in circumstances, she possessed a keep-sake – the personalised number plate, in her room in the care home so that she could identify with her previous life.

Possessions and objects and their effect on emotional distance were also carefully considered in the case of Jayne and her Mother. Jayne made the decision to move her Mother from the house she had spent 40 years in, to a bungalow closer to Jaynes own residence, against the wishes of her Mother. Jayne was concerned that the geographical distance between them (residing at opposite ends of the same city) was too far to travel to see her Mother, particularly if there was an emergency. A severe winter in, 2010 meant Jayne did not see her Mother for two weeks as she could not navigate the snow in her sports car. Her Mother was strongly against the move, desiring to remain in the house she had lived in with her husband (now deceased) and had raised her family in. For Jayne, these reasons were not justified and enforced the decision to move by implicitly threatening her Mother with decreased frequency of contacts and a resulting increase in emotional distance between the two of them if she remained in the familial home. Jayne felt a certain level of guilt in her actions and justified them by attempting to recreate the internal residence of the old house in the new property:

> We brought absolutely everything with us. And we even used
> the wallpaper in here, the same as she'd had in the other
> house. Because my sister had decorated in the old house for
> her right before she moved, so I went back and we got the
> same wallpaper, so that was the same. The layout is quite
> similar, other than Mums chair was over there near the
> cabinet in the old house. But the bedroom is exactly the
> same, same layout as her house. So we tried to keep
> everything as emotionally undisruptive as possible.

> Jayne

For Jayne, the recreation of the old living space in the new house solved the emotional difficulties her Mother experienced in leaving their former residence, however, Jayne's Mother still "*took a long time to settle in*", despite her actions to make the new house as similar as possible to the old, suggesting perhaps, that the re-creation of her old living conditions in the new house had limited success in minimising emotional upheaval.

4.1.4.3. Changes to 'self'

4.1.4.3.1. Manifestations of new identity

Findings identified a number of changes in the character of carers due to the emotional and physical demands of their caring role. Feelings of frustration, isolation and anger were common and some participants expressed more severe feelings of depression and even suicide contemplation. For William and Gary, the loss of their former identity had led to severe character changes as they experienced emotional distance from their former life and tension with their current life.

> Being a carer has been and still is the most challenging thing
> I have done in my life. At times being very frustrating, also
> mentally and physically tiring.

> Gary

Tim realised that his caring identity had brought about changes in his character, such as falling tolerance levels and increasing frustration and tension. Like William and Gary, Tim felt trapped in his new caring identity and emotionally distant from his previous identity, including changes in character traits.

> I try to deal with the frustration that I feel by slowly telling myself to "keep calm Tim, keep calm Tim" over and over…My level of tolerance seems very low.
>
> Tim

The changes in personality that Yvonne identified were very severe. She described a *"ferocious anger"* and admitted to losing her temper most days. For Yvonne, there was a feeling of unfairness regarding the carer role she has been *"forced"* to adopt and felt unhappy in her caring identity, whilst feeling she had done nothing wrong to *"deserve such an existence".*

> Every time the flashes of guilt I feel at my own impatience and inadequecy to deal with the situation rises to the surface but i am unable to relinquish my hold on my sometimes ferocious anger, shame and guilt at my behaviour.
>
> Yvonne

Tracy in particular felt that her caring role affected her disposition; both from the loss of her paid career and the isolating nature of her caring role. Tracy's self-identity was linked to her job which she had to give up to care for her husband. Because of this loss Tracy experienced changes in her temperament and disposition – going from being happy and confident and taking pride in her work to feelings of bitterness, resentment and invisibility. The nature of her caring task had changed her identity without her permission and she struggled to embrace her new identity of carer.

> Where once I was quite an outgoing confident person, I became withdrawn and less confident and even questioned my ability to do my job…I eventually had to give up my job and I felt very bitter about that, the rug had been pulled on my career and it had nothing to do with me! I felt a great loss and found life very difficult to cope with. I felt useless, lacking in confidence and tried to accept the fact that this was going to be my life now. I never bothered too much about my appearance, throwing on a pair of jeans and a T shirt - what was the point in dressing up, who was going to notice?
>
> Tracy

Changes to Tracy's self-identity also changed her physical appearance and she went from dressing up for work, putting on make-up and styling her hair to *"throwing on"* casual clothes because she felt invisible and devalued in her new identity.

Participants often discussed their ability to cope with their caring identity and the unending nature of the caring task. Carol and Harold in particular questioned their coping abilities and confirmed changes to their disposition. For Carol, the changes to her identity resulted in feelings of anger that she found difficult to control whereas Harold felt depressed and helpless.

> Sometimes I barely do cope and have discovered at nearly 70 years old that I have a bad temper. I never thought I had. I was always laid back and happy.
>
> Carol
>
> As to coping with the situation, I am not now coping well at all, I suffer from depression from sitting next to my wife who is crying with pain and there is nothing I can do to help her.
>
> Harold

Yvonne also identified a number of emotions experienced through the changes in her own identity because of her caring role. Unlike Carol and Harold she acknowledged a level of desire for the demise of her husband, not through lack of emotional attachment for him, but because of the pressures, frustrations and general negative experiences of her caring role. She revealed a sense of grieving for him and referred to her loss but felt guilty at these emotions, particularly when her husband had not yet died. The protracted death of her husband meant that her grief for him was also protracted which was combined with the stress she experienced in caring for him. Yvonne realised that her situation would only improve with the death of her husband and felt guilt for wanting her current situation to end, which ultimately meant the death of her husband.

> If my husband had died I could have mourned my loss and gradually moved on with my life but this irresolvable loss leaves anger and bitterness in its wake and an inability to enjoy the memories of the good times I've had with him and unable to come to terms with how things are as it just seems to go on and on.
>
> Yvonne

The ability to cope with the demands of caring was affected by the emotional distance participants felt from their previous existence and identity. Ken felt frustration at the lack of time he had to pursue his own interests because he

had no other ECE members to share his role. He also expressed constant worry which he was unable to *"switch off"* as he now had to be responsible for planning and decision-making, similarly to how Gwen described feeling.

> There's less time for me, and there's no one to share that burden… I just get so frustrated that I can't just get on and do what I want to do…I worry yes, certainly… I always have to be thinking ahead. I think that's one of the problems why I don't sleep properly. My mind's always alive to thinking oh, we need to do this, or we've got that to do tomorrow, of yes, I mustn't forget to do that. It's just constant and I can't just switch off. It's just not easy. But like I say, I'm not happy about it, not at all, but I deliberately go out of the way to make sure that I don't get down because that would be a downward spiral. It really would. We would have two of us that were poorly and I don't want that. I just have to sit and take it on the chin.
>
> Ken

Like Harold, Francine felt overwhelmed in her caring role. Her ability to cope became an issue, but improved with greater emotional proximity from those around her, outside of her caring role.

> Just every so often I can get overwhelmed and I think oh dear, I can't go on like this! How long am I going to be doing all of this for?... I went to the Doctors and said that I don't sleep very well and she gave me something…It's up to me really that I make sure I have these outlets and see people…I felt isolated and I was worried about the future.
>
> Francine

Ken described making an effort to *"not go down the spiral"* of feeling overwhelmed and for Bob, a need to be *"careful"* with himself existed due to issues with anger.

> There's no one to support me no. I seem to be supporting everybody else.
>
> [Researcher] How does that make you feel?
>
> Drained! [Laughs] I mean, I sometimes feel as though I'm juggling balls and I don't want to drop any of them but... the last couple of years in particular I have found myself losing my patience. I'm not as tolerant as I was…I think it's just sheer stress of coping with everything else. I think it's just a build-up. And I've got to be very careful with myself, you know...

Bob

Bob's isolation in his caring role resulted in feelings being repressed which led to unexpected outbursts of anger and greater emotional variability.

> So I've not got anybody that I'm close to that I can really trust, confide in.
>
> [Researcher] So who do you confide in?
>
> Ermmm, not many people. I keep it bottled up.
>
> [Researcher] And what impact does that have on you?
>
> Errmmm, [Pause] I get angry. But again, I keep it bottled up.
>
> [Researcher] And who are you angry at?
>
> Errmmm [Pause] I can get angry over the silliest things. I can be viewing something on say Facebook and somebody's hurt an animal and I can get ANGRY! At the person who could do that. I can't do anything about it, but you know, that's how I react to it…I think I've become much more emotional all round… Maybe it's because it's [caring] 24/7, I don't know.

Bob

Bob's caring tasks caused emotional distance for him as a person between his old identity and his new identity as a carer which resulted in anger he found difficult to control. The things that often made Bob angry were outside of his caring role, such as the abuse of an animal, but implied his reactions to such were disproportional and new to him since he became a full time carer.

Emily provided care to her Mother in law who in turn provided care for her husband who suffered a severe stroke, was bedridden and uncommunicative. Emily described how the disposition of her Mother in law Liz changed due to her caring role. Liz's pride in her ability to care for herself was reduced, however she still wished to be seen in a strong and positive light by those around her:

> The other week we… didn't have time to stay for dinner, so I said I'll do you a plate [of food] instead, but she wasn't too happy with that. She liked us there to cook for her. Well me actually. But I can't do that every week, some weeks I'll have to just take her a plate round and a bowl for Alex…And years ago she would have been offended if I offered to bring a plate round for her, she'd have been like, well, no, I don't want or need your food and straight away she was like, 'oh yeah is that alright?'...We know she's as stubborn as

> anything and she'll only do what she wants to do. I don't
> think she wants us to change our view of her. She was
> always strong and capable and I don't think she wants us to
> see her as any different.

> Emily

Liz wished to maintain emotionally close to her previous identity of strength and independence, however her circumstances (due to her caring role) dictated that she required greater help from those around her. This internal conflict with her own identity was a source of frustration for Liz as she struggled to acknowledge the need for help. This conflict was also shared by Jayne who revealed she had recently admitted to her caring role negatively affecting her life in a feedback form for the local Council. Jayne felt embarrassed by her admission and had always felt this way, but had been too proud to admit it on previous years' forms. A reluctance to admit the need for help and therefore the need for emotional proximity with others (in order to gain assistance) was in direct contrast to the character traits in the previous identity of the participants. This led to participants feeling a desire to reject the new caring identity, for fear of being considered weak.

4.1.4.3.2. Changes in roles and responsibilities

A level of uncomfortableness with the new sole responsibilities the new caring identity had created was common in the findings. Ken described himself as a switch that couldn't be turned off and Bob described himself as a wind-up toy which was continually wound, suggesting he felt a great need to *"unwind"* from the pressure of his new caring identity, but lacked the ability or opportunity to do so.

> I suppose I feel more like a wound up toy that starts to
> unwind and then someone turns the key again.

> Bob

Harold possessed feelings of resentment that due to his wife's illness, he was now solely responsible for all household tasks, and the family finances. The exhaustion Harold suffered from the changes in responsibilities left him with little emotional and physical reserves to assist him in dealing mentally with his caring role.

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> In the past my wife looked after all the household jobs with a
> bit of help from me, and she kept the household accounts.
> Now I do everything around the house, cooking, cleaning,
> laundry and accounts. This change in roles keeps me tired,
> frustrated and slightly resentful.

Harold

Tim revealed he was an expert in his professional field, regarded with respect and admiration by his colleagues and felt satisfaction that he was contributing to the improvement of wider society by being good at his professional role. He worked long hours but was greeted by a home-cooked meal, the opportunity to share the highs and lows of his day with his wife and then spend the evening relaxing and recuperating, ready for the next days working challenges. This identity ended completely with the termination of his paid work and was replaced with dis-satisfaction and concern that he lacked the ability to carry out aspects of his new identity (he had never cooked before and struggled to learn how to use the washing machine). He felt scorned by his new 'colleagues' (health and social care professionals) because he did not possess the correct skills to allow him to excel in his new role of carer. He lacked the opportunity to communicate his concerns and achievements, had to cook his own meal and his new 'job' had no finish time! This left him feeling bereft of professional satisfaction and a failure on the domestic front.

Similarly for Carol, household duties were shared between herself and her husband, but since she became carer she has had to carry the burden alone:

> Norman always took his fair share of housegold tasks
> throughout our marriage but is now unable or reluctant to do
> any, even when i try and give him simple tasks. I am now
> solely responsible for: driving; finances; all housework;
> gardening; home maintenance; diy, childcare; shopping;
> organising holidays; cooking.

Carol

Fear in carers regarding new roles and responsibilities and particular concern for their ability in their new roles, plus the sheer volume of work that the new roles entailed was indicated in the findings. Weariness, resentment and bitterness at the enforced new responsibilities were evident in a number of

participants, however, not all participants felt the changes to existing roles and responsibilities were unwelcome.

Francine and Catherine both felt a certain freedom with the new roles and responsibilities they experienced through their caring role. For Francine, her infirm husband behaved in a less controlling manner which gave her greater personal freedoms to pursue social activities but also to manage the household financially which was always the role of her husband previously.

> [Researcher] would you say he [husband] was the main decision maker - has that changed with his illness?
>
> Yes he was, and that's changed which is why I say I've got a bit more freedom now. I think I've got a bit more confidence now.
>
> Francine

Similarly, Catherine also has greater responsibilities for financial management which she revels in. The power she felt in taking an active role in finance bled into other aspects of her life whereby she could now take control of other aspects of running the household such as planning and implementing home improvements, redecorating interiors to her own specifications etc.

> I decide. I had some work done... I'm in charge of house maintenance!
>
> Catherine

4.1.4.3.3. Changes in the relationship between carer and care recipient

A number of participants disclosed severe changes in their relationships due to the progression from their old self-identity towards their caring identity. These participants often expressed feelings of great loss at this change. Participants expressed sadness that their previous identity of wife, husband and/or lover had been lost, to be replaced with the identity of carer. The role of their loved one has also changed from husband or wife etc. to the identity of cared-for, or even dependent or child, reported by some participants. The emotional distance created by this change was obviously very distressing for some participants:

> Our relationship altered beyond all recognition. I feel that I am looking after a stranger and that my husband has gone … We are no longer affectionate towards one another, we cannot share a joke, we cannot talk in any meaningful way and we no longer have a physical relationship.

> Carol

Whilst Carol felt she was now caring for a stranger, Susan now felt she was caring for a dependent.

> When I think about that I realise what an immense change has been brought about in just 5 years, my former close companion, good friend and constant support, my lover and beloved has become my dependent child.

> Susan

Yvonne's relationship with her husband had changed due to the caring role, which was not welcomed by either party. Not only had their relationship changed but all party's identities within that relationship had been replaced. Old labels of 'lover' or 'friend' had been replaced with 'carer' and 'dependent', creating massive emotional distance between those involved which could rarely be bridged.

> They are not the same person you married and are as unhappy with the situation as you are. It does not make easy bedfellows.

> Yvonne

Findings indicated a distinct change in relationships which were more pronounced when husband and wife became carer and cared for, rather than other ECE members. Due to the nature of ageing and specifically age-related illness such as Dementia, Chronic Heart Disease, Stroke etc. activities whereby couples formed and maintained their relationship and therefore identity within that relationship were lost or irrevocably changed. For Tracy, key bonding activities for her and her husband were the ability to discuss their minor problems, to debrief each other at the end of the day and feel a sense of shared experience. When this was lost through her husband's illness, Tracy felt the change in her identity and relationship and responded through feelings of bitterness and dissatisfaction.

My feelings towards my husband are now that of a carer and at times I feel like I am living with a child and not someone I used to be able to talk to and discuss day to day problems with. We are not 'husband and wife' now. He suffers badly with paranoia and there are days I could gladly walk away and let him get on with it.

Tracy

The loss of physical contact changed Ashleigh's relationship with her husband and therefore self-identity forever. She became very upset when discussing this change, demonstrating the effect it had on her even though it took place five years previously. Ashleigh mourned the loss of her husband – not because he had died, but because her identity as his wife had been replaced with the carer identity which did not include bonding activities such as physical affection. To Ashleigh, this loss signified the loss of identity and the need she had for physical affection from her husband was never again satisfied.

Some people especially at the drop in, they look after their husband - they're not husband and wife any more. You are a carer and a cared for. I used to try and go and sit on his bed with him and have a cuddle – 'don't touch me' he'd say, 'why?' I'd say, 'because it hurts' or 'I don't feel comfortable' or... and I used to say 'well, give us a kiss then' and he wouldn't and you, you lose all that.

[Researcher] Why do you think that is?

It was his decision. To put that distance there. I says to him 'well there's no point in me stopping in here if you're not going to give me a cuddle', 'oh don't be like that' he'd say. 'Well at least hold my hand' I'd say.

[Researcher] And did he?

Sometimes he would, sometimes he wouldn't…He was forcing himself to because he knew I wanted him to… I used to feel the loss of that physical contact with him, and that's when I became just his carer.

Ashleigh

For others, the change in their role has not affected the strength of their relationship, although the relationship itself may have changed. Susan felt admiration for her husband's battle with dementia and did not reveal the bitterness and hopelessness that other participants did. Susan did not

experience the complete loss of identity within her marriage that Ashleigh did, because she felt that the love they had previously had continued unaltered. In this way, emotional distance between the two had not been increased and the couple's identity of husband and wife remained in place.

> He is always so thankful for the help I give him and so appreciative of everything that is done for him. I admire him tremendously the way he copes with all the confusion in his life... I am humbled by the vigorous efforts he makes to understand the troubled world he lives in and by his grateful thanks… Although our relationship has changed due to dementia it remains strong. It isn't what we expected it would be - no one expects it - but so long as we can remain together and share our love for each other then I shall feel life hasn't been all bad.
>
> Susan

Harold also believed the strength of his relationship has not changed despite his wife's illness. Harold used words such as *"lucky"* and *"amazing"* to describe his relationship, demonstrating that the change in identity and resulting emotional distance experienced by Ashleigh and Tracy were not experienced by him.

> I am lucky in that I married an amazing woman and our trials and tribulations have not affected our relationship at all, we are still very much in love after 42 years of marriage.
>
> Harold

Changes to identity and relationships are not just present in those participants caring for spouses however. Chris described a time when his Father was still ill in Africa, shortly after the car accident. He clearly felt that this time was the point at which his relationship with Robert changed and Chris began to accept his new role and the caring responsibilities associated with it. However, Chris did reveal that acceptance of this role was accompanied by feelings of worry:

> I actually cherish those days in particular because, there was one day we went to the concierge and asked to borrow a wheelchair for my Dad. OK fine, you can have it for a couple of hours so I nicked it! And we then legged it from the hotel, got on a train and went to [unintelligible] just to do something different. But we've got photographs of... you know, Dad had a black eye at the time [laughs] and was wearing a baseball cap! But they are to me, very precious memories…I suppose they symbolise the change in the relationship between me and Dad. You know, I had to hold his hand when he

walked…I'm very glad I've got this new relationship with him… [although] I did find it hard, the worry.

Chris

Although the relationship and identities within it had changed, Chris felt that this allowed a greater level of emotional proximity between the two of them. Chris however, alluded to a distinct change in the identities within the relationship when he had to hold his Father's hand, much as his Father had done for him when he was young. This tender and emotive act compelled Chris to feel emotionally close to his Father, despite a flip in the carer-cared for dyad.

4.1.4.3.4. Changes in relationships between ECE members

Neil experienced a change in the relationship he had with his wife Judith due to caring for his Mother, particularly after the decision he made to move his Mother in with them, despite the protestations of his wife. Judith obviously struggled with this arrangement as Neil's Mother suffered from Dementia and her behaviour could be very challenging, including displays of physical aggression. Neil developed strategies to keep the two apart at weekends. Although Neil acknowledged the tensions he had created between his wife and himself, he felt powerless to assuage them. The change in his identity to carer had an impact on the level of emotional closeness he had with his wife but maintained that this mattered less than his new identity of carer.

> I have tested my wife more than I should have. We have had many a 'last chance'…You keep questioning yourself…Weekends are intolerable. Having to keep Mum away from Judith and be ingenious in thinking of ways to cope. I am past caring sometimes.

Neil

Neil obviously felt divided in his roles between his old identity of husband, and new identity of carer which led to feelings of frustration and acrimony.

Disharmony among ECE members was often experienced when interpretations of pulling your weight were not shared between them.

Karen felt frustration towards her brother in law in caring for her Father in law. Karen felt that the fact that Chris lived some distance away was not a good

enough excuse for him to not take greater responsibility in the ECE's caring role. She felt the fact that she had two children who required her care trumped Chris' claim that he was too busy and far away.

> Chris's only responsibility is his wife…and I said to Edward we've got 2 young children that also need our attention. And I found it quite hard that Chris very rarely came up, and if he did come up it would be for one night, and Robert needed more than that, he needed, you know, the company and he needed assurance from Chris.
>
> Karen

Differing opinions on what constitutes good care caused increased emotional distance within the ECE as the group struggled to realign their identities, roles and responsibilities to include the caring role and balance this identity with their other former and continuing identities. This disconnect was also revealed in Karen's relationship with her husband.

Edward recognised that his relationship with Karen had altered because of the need to care for Robert. Arguments regarding the frequency and nature of contact became more common, with both parties feeling that they are were in the right. Edward felt that Karen was being unsupportive, making excuses such as the children's attendance at football for not scheduling in a visit to Robert's. Edward suggested that these arguments were settled by *"meeting in the middle"* but then implied that in fact, he backed down and attempted to find a resolution to the problem some other way. Edward felt that the difference of opinion was at least in part, due to the differences in their upbringing (Edward was raised in a small country village whereas Karen grew up in a deprived area of a northern English city.) Edward also used emotive, guilt-provoking arguments in attempts to change Karen's mind, implying that she would feel differently when it became her parents that required care.

> Obviously our lives have changed as well, because now we have someone who depends on us a little more…And at nearly 40 years having to change the concept of your life, I think she found a bit difficult at times. Ermm, so in that respect that's sometimes when you have a bit of debate about stuff. Me and Karen will sit down when we're planning our meals and I'll say 'shall we invite my Dad down?' and she'll say, 'oh, yeah alright then'. And I'll say 'what about going to my Dads on Sunday?' and she'll say, 'oh we can't

do that because we've got football on' - well why can't we? 'Oh because we've got this to do and that to do' and I'm like, she doesn't sometimes think, we'll just go see my Dad. And this is how arguments start. I'll say 'well let's have a look when your Mum or Dad are on their own and you say that to me we can't go because we've got football!'

So what happens when you have these discussions then? What's the outcome?

Ermm, we sort of meet in the middle I suppose. But I'm quite chilled out, Karen's hot headed so sometimes I'll just go, I can't be arsed with arguing, do what you want! Yeah we'll just do that, you know. And then I'll get around it some other way. I'll be level headed about it.

Edward

Edward felt great pressure to balance his new identity with his previous identity and felt that Karen could do more to assist him in this, resulting in increased emotional distance between the two of them.

Margaret felt some conflict in defining her relationship with Catherine, the neighbour she cared for. Although she acknowledged that she was a paid carer, she also provided extra duties which were not paid for, leading to confusion over the status of the role – carer or friend? Margaret was visibly upset when recounting the tale of accidentally charging Catherine for an extra hours pay and felt resentful that the extra she did for Catherine was not noticed, or that it was actually expected in the role of friend. Margaret al.so expressed fear that her husband Neil would find out about the additional unpaid hours she did for Catherine, particularly because Catherine was financially secure and lived in a large house with antiques etc. Margaret revealed that she actually lied to her husband regarding the extra hours she worked and told him she was paid for them, when in reality she was not. Margaret appreciated that her role of carer had become blurred with Catherine – at times she acted as paid carer and at other times as friend and neighbour.

Catherine pays me. And I did a bit of shopping for her so I wrote all that down. But I added an extra hour down, totally by mistake!![Laughs] Catherine knew! She said 'Margaret, you've only done 6 hours!' I said 'oh my God!' I felt awful, I felt awful, I said 'Catherine I'm not trying to diddle you' I said, 'well good on you for checking', so she said 'well I feel awful saying!' [Laughs]…'No', I said, 'I'm glad you have'. But all

that might maybe go through her books - I don't know. I don't know but yeah, I mean I haven't said anything to Neil, but when I go to take Catherine I'm about 2 hours, but I mean she's never said... you know..

[Researcher] What, 'I'll give you extra?'

Yeah...

[Researcher] So why do you do it then?

Well, because I feel sorry for her. And, well no maybe not sorry for her, I Like to take her, I mean it's only once a week, maybe two...but Neil says, well as long as you're getting paid!

[Researcher] But you wouldn't think to say anything to her?

I couldn't. I couldn't ask her. I could not ask her at all. Because, well, I don't want to upset her shall I say? And that's me maybe being daft. Because my afternoon is taken up going to [local town]. And that could be £20. But, why… you can't!

Margaret

Margaret accepted that the level of emotional proximity she enjoyed with Catherine was unclear and the identity she took with her changed between carer and friend. Margaret was even willing to risk arguments with her own husband rather than attempt to clarify her identity, such was the level of awkwardness she felt the process of clarification would provoke.

4.1.4.3.5. Love or obligation?

Findings indicated that the emotional connection carers felt to their care recipient was often based on feelings of duty and obligation rather than love and affection. However, many participants confirmed feelings of all four sentiments when expressing their reasons for taking on their caring role.

Motivations for caring had a direct impact on the self-identity of the carers and whether it changed with the advent of caring duties.

Gwen, Ken and Bob felt that the obligation and duty attached to their wedding vows, in the sight of God make them unable to negate their caring role, despite the challenging reality of the experience. Theirs was a duty, a promise made in

Church which could not be broken without serious moral and ethical consequence. However, both Gwen and Ken considered the promises made historically were not informed of the reality of caring for each other in sickness – the reality of the future situation was not fully understood or appreciated and the consequences unknown on their wedding day. For Bob, motivations to provide care were from a genuine love for his wife which still endures, but also because of his duty as her husband.

> Forty four years ago I stood in Church before God, the Minister and my family I made promises, one of which was to stand by my husband in sickness and in health. Little did I realise what that would mean in the future.
>
> Gwen
>
> At one point I was quite angry. But over time I've recognised that what I can't cure I have to endure and I've learnt to accept that. I'm not happy about it, but at the same time, I made an oath many moons ago in Church in front of all my friends and I'm still here doing it, And that's important, but that's not to say that I'm enjoying it because I'm not.
>
> Ken
>
> When I got married it was for better for worse, richer for poorer, in sickness and in health, you know, it's my duty. I love my wife and it's something I will do for her. I love my parents so I do for them, I love my sister-in-law's so I do for them. It's a duty, I want to do it, but it's still my obligation…I have a duty to a lot of people.
>
> Bob

The obligation and duty felt through the religious and social act of getting married was important to these participants. Their identity – that of husband or wife, was one confirmed by God, and in front of their family and friends. Because of this, their label of husband or wife could not be removed, especially in response to the sickness they vowed would not change the relationship or their identity. By maintaining the identity of husband or wife, the carer responsibility becomes nothing more than a role to be acted upon, not the replacement of identity. The participant maintains the link to self-identity prior to caring and so does not suffer the grief of its loss.

For Ashleigh and Vivienne, their promises were made directly to their care recipients. Again, this created a moral obligation to stand by these promises, regardless of the cost to themselves. To negate these promises would have meant a failing of their own moral code, a key aspect of their self-identity which was not acceptable to either participant.

> He made me promise him that I would stay at home and look after him. He didn't want to go into a home or into hospital or respite. And so I nursed him right up to the end.
>
> Ashleigh
>
> I promised him I would look after him at home and not put him into care but even though I had help, I still found it hard work.
>
> Vivienne

Yvonne confirmed that her driving force to provide care to her husband was the moral obligation she felt for him. However, this conscience became a trap, not allowing her to free herself from her caring role at the cost of her own wellbeing.

> It's an admission that'll resonate with many people caring unexpectedly for loved one. We never chose to be in this position and we certainly never trained for it, yet here we are, unable through our moral consciences or love to do anything other than care.
>
> Yvonne

Gary expressed the struggle he had experienced in the caring role but also acknowledged that this could be rewarding. He confirmed that his wife remained his best friend despite the changes in their relationship.

> At times being very frustrating, also mentally and physically tiring. However when I see Julie happy, laughing and singing, the task can be very rewarding. Julie is my best friend; my aim is to care for her despite all the challenges and aggro I may encounter each and every day.
>
> Gary

The positive aspects of love and affection that remain in the relationship, despite the changing nature of it were described further by Gwen, Yvonne, and Tim. For these individuals there was no regret in their caring role and a strong sense of dedication and love. The change of identity from husband or wife to

include carer had not affected the emotional closeness they shared as a couple. Their existing identity had expanded to include the caring role rather than being replaced by it. This suggests that the change in identity from the previous identity to that of carer is a process which may occur by degrees. Emotional proximity between the individuals was able to contribute to the maintenance of the self-identity prior to the caring role and to allow the role to be absorbed by the existing identity. The combined motivations of duty as 'husband' or 'wife' and of genuine love and affection meant that, by definition, the identity of the carer remained that of husband or wife and was not replaced. Caring became an additional role to be fulfilled and not a replacement identity.

> We have a strong marriage and that helps my caring role. I would never think of leaving him as I have heard other people have done in similar situations.
>
> Gwen
>
> Did I love my husband? Yes of course I did and I do not regret one day I looked after him.
>
> Yvonne
>
> I would not change a thing, even though it is hard work looking after her. She is my whole life.
>
> Tim

In contrast to this, Ken felt that the love he had for his wife had had a cost to himself. He did not feel that the caring role had been incorporated into his previous identity; rather it had been replaced by the identity of carer, despite the genuine love and emotional proximity he enjoyed with his wife.

> What drives me along is the love I have for my wife, I wouldn't want to change that, but nevertheless I'm paying a very severe penalty for that.
>
> Ken

Ken described the *"severe penalty"* he referred to as the loss of his own life, his own identity. Although acknowledging that he wouldn't wish to change his relationship and being driven by the love they share, Ken did not feel happy in the replacement of his identity with that of carer and expressed the desire to access parts of his previous identity, such as social occasions with friends.

Unlike Ken who did not welcome his carer identity, Neil actively sought to replace all aspects of his previous existence with his caring duties (such as giving up work, moving his Mother into the familial home and dedicating his entire life to caring for her). However, still faced daily struggles in caring for her. Because of her mental health, her behaviour was challenging and Neil described "*barely caring some days*". Although accepting of his new carer identity, he experienced increased emotional distance from his Mother, due to her challenging behaviour. However, once his Mother was diagnosed with a physical illness his feelings towards her completely changed. He implied that he did not consider her mental illness as being *"properly poorly"* and that it was only when her physical health was compromised that he was able to embrace an emotional connection with her once more, despite her actual behaviour not changing at all:

> Mum diagnosed with breast cancer… That changes everything. Now she is properly poorly and suddenly the love comes flooding back. Her behaviour has corroded our feelings. She has pushed us to our limits and only duty has kept us going. Now love sustains us once more.
>
> Neil

Nothing in Neil's Mother's conduct had changed. She still continued to present challenging behaviour, periods of aggression bordering on violence, particularly directed towards Neil's wife, however the diagnosis of a physical illness rather than mental brought increased emotional proximity between the two. Where once a sense of duty had forced him to continue in his role of carer, the diagnosis of cancer inspired love and affection as the motivating factors for caring.

Catherine (as the care recipient) implied feelings of guilt that her ECE felt guilty that they don't spend more time with her. She described an incident when her son wished to come to stay with her and was going to call in on his way home from a business trip, late at night, rather than going straight home to his own family:

> I said it's not worth it, nothing is worth it, people are more important, spend all the time you can with your family, that's the most important thing, for them and for you.

[Researcher] Do you think he feels guilty?

I think in a way he does. And I keep trying to say, 'don't'. And he said he was going to try and get up once, so I said, you know, do the safe thing. He said, I know what you're trying to say Mum but I'm really going to try… I think in a way he does feel guilty, although I keep saying don't. And the family don't press him, for obvious reasons, they don't want to add to this.

Catherine

Catherine and the remainder of the ECE were in agreement regarding other duties and obligations and attempted to minimise any tensions surrounding competing demands by insisting their caring role was not crucial due to the support from formal paid care. Rituals of contact developed between the members with emotional attachments which assisted in maintaining the relationship. For example, Catherine had an arrangement with her son (who resided in Spain) not to contact her whilst she watched her favourite TV programme. This caveat had developed into a display of affection and amusement for both parties and served as a method for ensuring an emotional bond between the two – an affectionate joke the two shared regarding Catherine's addiction to the TV programme 'MASH'.

Catherine's family were geographically diverse, with some members residing in other countries and when questioned, Margaret, Catherine's neighbour who provided care for Catherine felt the family could not have done more to assist in caring for their Mother. It was clear that Margaret felt that career success was a valid reason for maintaining distance from the caring role, which she felt was supported by Catherine herself:

No, I don't think so. Because I don't think Catherine would let them. I think Catherine would rather pay somebody to do, than have her family on her doorstep and I think her family do what they can. That is my personal opinion!

[Researcher] Why do you think Catherine would rather pay someone to do it?

Because they are all working. And they've all got high-powered jobs and you can't just - as you know, down tools can you. This is the thing…they're not your average..!

Margaret

Catherine and Margaret's viewpoint was that the ECE members should feel no duty or obligation towards the provision of care because their duties lay with their own families and the pursuance of career. The ECE members maintained a level of emotional closeness which did not include transferring their identity to one of carer, or even expanding their existing identity to include the role of carer, and this was accepted by all ECE members.

Dorothy also considered that an ECE's other duties and obligations should come before their caring duties. She felt competing demands for time was a valid reason to maintain previous identities, without increasing emotional distance as a result:

> [Researcher] Did you ever feel that someone could have done more for you?
>
> No... Because I've always said as far as my family's concerned, they are married and their life is their life. What they do is because they want to do it, not because they are obligated. I don't feel that way, so...when they got married I always said, the old fashioned way, when you get married your home's your home and that's how I've always felt.
>
> Dorothy

Conversely, Ian felt that emotional closeness to his wife demanded the change in identity to carer. Ian possessed a strong relationship with his wife and the rest of the ECE and was one of very few participants who expressed happiness and contentment with his situation. Ian felt that his main duty was to care for his wife and that a by-product of that was that he must look after his own health:

> [Researcher] Do you ever feel isolated or lonely?
>
> Never. Never. I don't no. I'm so lucky. Why would I feel isolated? I'm surrounded by my family… it is a worry to me that I am getting a little bit doddery and I am being more and more careful not to have any falls because of my role with Pam.
>
> [Researcher] So do you mean its having almost a protective role? Like you are keeping yourself healthy for Pam?
>
> Protective influence, yes that's it exactly. She needs me. So I am doing my best, for her, and my family…
>
> [Researcher] Do you do it for you too? [Laughs]

[Laughs] well yes of course, but I see my most important role as looking after Pam and everyone knows that!

Ian

Ian's role was that of carer for his wife. He accepted and embraced this role completely and also had an emotionally close relationship with his wife, maintaining both the carer identity and relationship identity of husband. He saw his main obligation as providing care which was his main motivator for ensuring his own health. Ian was able to embrace both identities of husband and carer; both identities were maintained and one did not replace the other - the only participant in the study to be able to do so.

The majority of participants desired emotional proximity with their ECE due to positive, loving relationships with them and some decided that this could only be maintained through the development of a new self-identity of carer. For other participants, love and affection were not necessarily motivating influencers for the provision of care in the ECE. Katie was one participant who spoke derogatorily about her care recipient and expressed a number of tensions within the relationship, implying that she acted out of a sense of duty to her husband, rather than to the care recipient herself.

That's my role, to maintain his relationship with his Mum… I do the things I do out of affection for John, because I know she put John through a lot of crap when he was living at home… So it is for John…She's a liar unfortunately. She lies about everything. But then that's attention, whether it's positive or negative it's still attention…she doesn't like to be seen to be... bad.

[Researcher] To you too, or to others?

Oh no! Completely! yeah, she'll call them all sorts to me, oh you know that fat man that comes in, and I'm like it's a woman, you know it's a woman, she's got 10 kids! She's terrible, she's really bad, oh, she's a complete bitch at times. She can be horrendous about them, but not about others… She's stroppy and not very nice sometimes. She can be a bitch.

Katie

Katie does not desire emotional closeness with Ann because she actively dislikes her. The reason Katie provides some care for Ann is out of a sense of

love and obligation to John - her husband and Ann's son. Because of this, she has no desire to change her self-identity to reflect the caring role and partly resents the attention Ann takes from her husband. Katie had a serious argument with Ann when she had just undergone a hysterectomy and felt her own needs were eclipsed by Ann's. The aspect that angered Katie was the impression that Ann was not trying to stay in good health, and had not considered the impact that this would have on Katie (although the motivation for Ann's behaviour was not considered by Katie). Katie used the threat of emotional distance in an attempt to change Ann's behaviour:

> I fell out with Ann once, just because she couldn't be bothered and she was just being lazy…When she was in the half way place I said to her, 'oh, have you had anything to eat?' 'Oh I'm not hungry'. 'What did you have for breakfast?' 'Oh I had this and that for breakfast' so I got the paperwork and she said 'what are you doing?' So I said 'well they write everything down Ann so we know...' 'Well I didn't want it then', so I said 'and you're not eating now?...Ann do you know what, I couldn't give a shit'. 'What do you mean' she said, I said 'you know, you can't be arsed and you're going to fall and that will mean I'll end up back in hospital because I've had a hysterectomy and obviously you're not bothered about me, it's all about you, so, I'm going' and I walked out. 'I'm really sorry' she said, 'no, you're not sorry', I said... 'Until you decide you can look after yourself I'm not coming round'… She did seem to genuinely recognise that she had upset me and I didn't go round. But the others were all like, 'oh you've got to go' and I was like, 'no!' Because then she's won. She's done it for attention and she's got the attention… I suppose it was a bit of emotional blackmail to get her to think of us instead of herself, you know, in a good way. Because she walks over everybody.

> Katie

Katie experienced feelings of emotional distance between herself and the remaining ECE as her own needs remained eclipsed by Ann's when she herself was poorly. Interestingly, Katie felt that Ann was ungrateful, had never expressed her thanks and was manipulative and untruthful. Katie's husband John on the other hand expressed how grateful he believed his Mother to be and described her character as willing to put herself out for the sake of others (for example eating meals) – in direct contrast to the major argument Katie described.

[Researcher] I know you said that you've been poorly, and you had your operation. Do you think that your needs were met, even with your and everyone else's involvement with Ann?

No, I was completely pushed aside. Completely. It's not like John could afford to take time off work, because I was off work. I was so lucky that I was OK, back driving early and everything, because Ann still came first with everyone.

[Researcher] How did that make you feel?

I had to keep going, caring for her…I don't think I was appreciated enough. I don't think they realised the severity of what I was going through with my own health and trying to care for her too. She didn't appreciate me and neither did the rest of them.

[Researcher] Do you think she does now?

No, I don't think she gives it a second thought, it's gone, it's happened, hasn't it? She's never thanked me, ever for anything. It's expected. It's expected.

Katie

[Researcher] So what is her attitude to that then? Is it like she is very grateful for what you do, or is it more that she feels entitled to it?

No I don't think it... there's no arrogance to it, she's very grateful, always very very grateful.

[Researcher] Does she... fib to you?

Yeah. Yes she does. You know, not bad lies but she does. Yes she tells us that she's done things when she hasn't... She's fibbing to stop us worrying. I think that's all it is… she used to fib about eating. Again it was to pacify us, for us not to worry about her. So she was telling lies about eating meals and then she'd say that she'd eaten something and then we'd check in the freezer and it would still be there, we'd check in the bin and they'd be no box there, so we knew she was lying about it, so it was purely just to stop us worrying about her… It was almost like she was just eating a bit for you, rather than because she actually wanted to.

John

John felt that the caring duties he and the rest of the ECE performed were done out of love and affection. He felt his efforts were appreciated by his Mother and

assumed that the remainder of the ECE felt similar regarding their own caring roles:

> We was all really concerned…. It never felt like a burden to be honest. I think we all wanted to go and spend time with her, I think that's when you start to think, I don't know how long I'll have my Mum for... As far as I was concerned I wasn't going down because of an obligation, I was going down because I genuinely wanted to.
>
> [Researcher] So when you go round now, is it... do you have a routine? Does she expect you to go on certain days and things?
>
> No my Mum's not like that, she's just grateful that you come round. She's... if you didn't go and see her for a couple of days she wouldn't say you know, where have you been?... well she might drop a sarcastic comment in jest, like 'it's been months since I've seen you', 'hello stranger', that type of thing but she's alright, she doesn't give you grief for not turning up, she doesn't expect you to be there, she's just happy for you to be there, you know, she's grateful.
>
> John

The 'truth' of the situation and how ECE members saw it all depended on their level of emotional distance from both Ann and the caring situation. ECE members who felt distant, or even dislike towards Ann saw her as an ungrateful liar and resented the intrusion of the caring role on their self-identity. Others who felt emotional closeness to Ann and a strong carer identity saw her as always grateful and a pleasure to spend time with. Interestingly however, Katie provided care tasks for Ann whereas John engaged in social visits only but viewed his own identity as a carer for his Mother.

ECE caring can also be confounded by historical elements of the relationships and indeed emotional distance between ECE members. Jill's ECE consisted of her ageing parents, her brother, husband and children. Her Mother suffered from advancing dementia and her Father was struggling to cope with her behaviour. Jill and her family were very close and always had been, and as the eldest child she felt expected to take lead responsibilities in helping her Dad cope, just like she had whilst growing up. Jill also felt an expectation of reciprocity in her caring relationship – that her parents had looked after her growing up, assisted with childcare so she could work and helped her

emotionally and financially through the break-up of her first marriage. It was now her turn to care for her elderly parents as an emotional quid pro quo. Jill expressed a desire to provide care from genuine affection for her parents, but also suggested some feelings of duty - like caring was something she 'should' do, as eldest adult child, even though she felt no pressure to actually carry out the duty from her parents:

> [Researcher] How does that make you feel? That responsibility almost?
>
> Yeah, I don't mind, I don't feel no pressure, like I said I would happily go out and help my Mum and Dad a lot more than I already do if they wanted that. So... It'll come to the point maybe one day where I'll have to look after my Mum if anything, if anything ever happened to my Dad. They are both in their 80's so... they are doing very well but... I don't feel obligated at all. My family have always done everything they can for me, my Mum and Dad still help me now financially now if we need it… I mean I do the same with my children, I do whatever I can for them. I've never felt obliged to my parents at all. I just feel like I should do it, but not that I have to do it. I want to do it.
>
> Jill

Emily has a complex relationship with her Mother-in-law Liz and expressed feelings of duty and obligation as well as feelings of reciprocity in the caring task, similar to those expressed by Jill. Emily provided care for Liz, who provided care for her Father in law, but also implied a certain level of dislike towards Liz similar to Katie, however for Emily, this was tempered by feelings of sympathy at Liz's situation and exclusive carer identity. Emily acknowledged that Liz felt uncomfortable regarding the acceptance of the status of care recipient and detailed covert caring methods she used to minimise negative feelings regarding the reality of the situation. These methods included requesting baby-sitting as an excuse to create emotional distance between Liz and Liz's own caring duties (Caring for Emily's Father in law) and requesting assistance with tasks as an excuse to allow Emily to assist with them.

> It's... I feel sorry for them more than anything because it's awful… And I do get frustrated at times because we can't do anything. But at the end of the day I couldn't ever leave them… You can't... you've got to look after them haven't you?... She hates people helping her because they shouldn't

have to, because to her we are the kids. She says you shouldn't have to help me, I should be helping you, I can't rely on you. But I'm like, well, that's what's happened, that's how it is. You looked after us, you looked after our kids, and now you need me to help you, it's just how your life changes isn't it. But she won't accept that. She hates it, really resents it so we have to tread carefully….If we help her, we have to do it in a way that she doesn't realise, like I'll say, I'll come and sit with Alex if you can have my kids for an hour after school so she thinks she's doing me a favour, when I don't really need the kids looking after but I know she needs time on her own. I have to bargain with her I suppose, she's so stubborn. Or I say, can you show me how to do so and so, so she feels like she's helping, but I really know, but then I can help her do it you see?

Emily

Unlike Jill's situation, Liz felt no connection with reciprocity in the relationship and still saw herself as the parent – her self-identity was effectively carer of her husband, but also as parent to an adult child where a certain level of caring was still expected.

Emily experienced frustration with the rigid expectations of Liz, but felt duty-bound to honour them. Emily was also frustrated by competing demands for her time and feelings of guilt at having this frustration. Ultimately Emily felt duty-driven to provide assistance because she felt she was needed. This need required Emily to adopt the carer identity even though she remained somewhat emotionally distant from Liz. Emily described a situation where she had promised to take Liz shopping, but had also committed to attending her niece's birthday party. Emily attempted to change the arrangement with Liz, who then got angry, made Emily feel guilty, and subsequently made Emily forgo her attendance at her niece's party. As a result Emily felt resentment towards Liz and Liz felt that she was unimportant to Emily. This incident caused tension within the ECE and actually increased emotional distance between Emily and Liz, despite the fact that the contact was maintained because of the argument. Emily viewed contact with Liz as yet another demand on her time which is unwanted and unfair.

I can't please everyone all the time! I'm busy, I've got kids, I work, it's another pressure.

Emily

Emily felt that Liz used guilt as a method for securing further emotional interaction with the ECE which led to further feelings of resentment for Emily. Emily clearly felt an obligation to both her husband and Mother in law to attempt emotional closeness within the ECE – feeling that she should do this, with particular reference to the expectations placed on her through her gender. Emily described a situation where she regularly went to collect Liz's prescription for her. On this occasion Emily had been unable to pick it up that day, but had told Liz she would pick it up the following day, due to being at her paid employment. When Emily went to pick up the prescription the following day she was told by Liz that she had asked the formal carer to do it instead. Emily felt that this was deliberate manipulation in an attempt to make her feel guilty:

> She tells me that they've gone and then I'm thinking, has she not asked me because I've got 2 kids and I'm busy and I've got too much on, but then is it a bit of a guilt trip - otherwise why would she tell me at all. It's like she's saying, 'oh you haven't got time for me, I'll have to get someone else to help me'.
>
> Emily

Emily admitted that this made her feel *"put out"* and guilty that she hadn't collected the prescription the day before. Emily also felt angry at Liz because she felt asking the carer to go was her way of *"having a dig"*. Emily was frustrated because her former identity was being transformed to a carer identity without her acquiescence. Caring for Liz was taking over many aspects of her, and her family's life and Emily felt an added responsibility to ensure that emotional distance between Liz and her son (Emily's husband) was kept to a minimum.

> We are doing as much as we can do. It's not easy, and we have little kids and we both work, we can't do much more. I don't know how we could fit anymore in. Every weekend we are there, that is our weekend. We can't do anything. But it's his parents isn't it, like I say, it's what you do isn't it? I suppose Richard does it out of love, I mean I get on with them of course, but I guess I'm pushing Richard more because it's what you should do, so that's the duty bit isn't it. But men just don't see things the same way. They don't think like we do…I'm always saying 'well are you ringing your mam' and he's like 'oh yeah'. I think he would forget though if I didn't remind him.

[Researcher] So would it be a black mark if you forgot to ring one night?

Oh God yeah. Yeah, we'd never hear the end of it. Some nights we might have gone to the boy's friends and she's rang us when we haven't been in…and she'll be like, 'oh I rang you, rang a couple of times', and we're like, 'oh yeah, we weren't' in!' - Like we are not allowed to do anything if it interferes with what she wants from us. I suppose it's like another stress, another, well I was gonna say chore, but it's not really a chore, just another thing that needs to be done. A duty maybe.

Emily

Like Jill, roles and responsibilities in the ECE prior to caring also affected Jayne. Jayne felt very strongly that it was her duty as eldest daughter to take the lead in the ECE. This she felt, was her responsibility long before her Mother became ill. Jayne became visibly upset when discussing the duty she felt, expressing that it is what her deceased Father would have expected. Jayne undertook this responsibility from a sense of duty, more than love and affection for her Mother, because she *"wasn't the best Mum":*

It is my responsibility to take care of my Mum. Yes.

[Researcher] Why is that?

[Pause] [Interviewee starts to cry] Because of my Dad. It's what my Dad would have expected and... I don't want him to be disappointed in me. But, I also take it as my responsibility. Because I'm the oldest…She wasn't the best Mum, I mean my husband says 'Jayne why are you doing all this for her, she never did nowt for you!' And I just say 'no, that's not the point'. I'm the eldest, it's my responsibility, that's just who I am…I'm stuck with the character I am and that's it, you can't do anything about it.

Jayne

Jayne felt obliged to continue in her lead role within the ECE due to patterns and roles assigned years previously. Emotional closeness with her Mother was not the motivating factor in this case, unlike for Jill, but like Emily, Jayne felt a duty towards another member of the ECE – in this case her Father who had died some years previously. Jayne took her identity of carer very seriously, expecting other ECE members to fall into the roles they too had been assigned when growing up. Jayne felt that her Mother always *"played the victim"* and so

was always taken care of by the ECE, namely Jayne's Father. Jayne's younger sister was actively disliked by Jayne and described as *"selfish"*, despite Jayne's admittance that she had visited her Mother and cleaned the house for her. Jayne felt threatened by the decreased emotional distance between her Mother and sister and told her sister to stop cleaning as she herself would do a better job. Despite Jayne's attempt to control the emotional proximity of other members to her Mother, Jayne complained fervently that her Mother thought of her sister as the good and helpful one, arguing that she had only cleaned twice, getting all the praise whilst Jayne who cleaned every week got no praise. Jayne could not conceive the possibility that her sister may have done more for her Mother so that Jayne's demands were lessened, if Jayne had not rebuffed her. Jayne's caring identity was most precious to her, something to be guarded and fought over if threatened. Like Katie, Jayne needed to be needed and so isolated her Mother by ensuring emotional distance between her and the remainder of the ECE was maximised at every opportunity, despite admitting that the pressure of being sole carer for her Mother was having a negative effect on Jayne's well-being.

Jayne was not alone in jeopardising her own well-being to maintain her self-identity as that of carer. Fred took his feelings of obligation and duty to care for his wife further, admitting that he did so at the expense of his own health. Eventually Local Authorities stepped in and forcibly removed his wife to residential care (because he had not been able to provide his wife with a sufficient quality of care), but he still felt it was important to ensure minimum emotional distance through visiting his wife every day in the care home. Fred maintained that he did this not because of the obligation he felt, but from a genuine desire to continue to be part of her life, and her a part of his.

> I thought my obligation was to look after my wife at home, and I was quite prepared to. It didn't matter what hassle it took, I didn't mind doing it, but I didn't see that I was running myself into the ground… When you marry you marry for better or worse and if things are worse you're supposed to get on with it. I just took it as part of the role the husband plays. That's why I go every day to see her. I don't have to go, I want to go. I don't look it as an obligation, I want to feel part of her life, even though she's in the home.
>
> Fred

Fred divulged that he spent every single morning in the care home with his wife and left only after giving her lunch (a task he insisted on, despite the staff of the care home being reluctant to indulge him). Only through high frequency and duration of contact could Fred maintain his identity as carer and minimise emotional distance between himself and his wife. Fred was unwilling to renegotiate his identity now he was actually no longer caring for his wife and so insisted on renegotiating previous rituals (such as feeding her) in an attempt to uphold it.

4.1.4.3.6. Piety and self-sacrifice

In most ECE's self-identity as a carer is linked to the emotional proximity (or distance) between themselves and the care recipient, however there were some participants who did not take this standpoint. A number of participants expressed virtuosity in their caring roles and displayed opinions suggestive of a higher purpose, achieving greater than the expectations placed on them by family, friends and society as a whole. This opinion elevated their self-identity from mere carer to 'carer extraordinaire', selfless in thought and action and superior to other carers who did not embrace the carer identity so completely, and nothing to do with the quality of the relationship between carer and care recipient.

Neil in particular cared for his Mother at home and recounted many opinions that confirmed feelings of duty and obligation and that he had no choice in the matter. Neil also felt that individuals who provide part time care or have formal assistance in caring are pretending to care. This scale of commitment vocalised by Neil demonstrated feelings of superiority to others in caring situations. That only through self-sacrifice and the development of the extreme caring identity to completely replace any former identity could one truly label themselves as carer:

> So many come out with "I don't know how you do it" or "I couldn't do it". One woman in the village asking about Mum ending the conversation with the parting shot "... ruining your life". I have the completely opposite view - how can you not do it? …she expected me to look after her and how could I not do so?... I still don't understand how people can do it for a baby but baulk at an adult. You are made to feel as if you

are odd, such is the social acceptability of giving the job to someone else (e.g. care home) while pretending you are a carer!... That is why I cannot get on with on-line support forums which seem to be populated by these people. Not for me thanks. That may be harsh as being able to care full time depends on your circumstances. What will I say is caring part time and caring full time are completely different and you need a determination that says in the darkest time "I will not give up - there must be an answer tomorrow".

Neil

Neil's self-righteous stance with regards to caring saw him attempt to categorise people into carer and non-carer based on the emotional cost to the carer and the carer's former lifestyle. If this cost was not great, he believed it to be insulting to label that person a carer. His viewpoint allowed only those who sacrificed themselves in pious pursuit of the care recipient's wellbeing to be truly thought of as a carer. For Neil, the carer identity had little to do with the emotional connection between carer and cared for and everything to do with self-sacrifice.

For other participants, an expectation of self-sacrifice was present from the care recipient themselves. Both Katie and Emily felt that it was in fact their care recipient who displayed martyrdom in their words and actions within their ECE in an attempt to minimise emotional distance within it. The care recipient's expectations of self-sacrifice and reverent attention from their carers added feelings of frustration and guilt to the carers experience in the caring role. Martyrdom from the care recipient also resulted in feelings of resentment for the carer and in fact, instead of decreasing emotional distance, often ended up increasing it further.

Katie identified that her Mother in law Ann suggested putting herself in a residential care home as a way to control the situation, to enforce feelings of responsibility and guilt on the members of her ECE and ultimately, as a means for getting her own way.

> If she's on one when we are asking her to do things, she'll say 'oh, just put me in a bloody home then!' So I'll say, 'well is that what you want us to do?' Its mind games, you have to play with her. 'If that's what you want Ann we can contact Social services and we can go look at some places. If that's what you want to do, we'll do that for you.'

Katie

Katie felt emotionally strong enough to call her bluff - to remove the power that Ann felt she got from playing the martyr, however Emily did not.

Emily felt that her Mother in law was unrealistic regarding her ability to care for her husband Alex. Her refusal to accept outside help but frequent emotional outbursts regarding her ability to manage the situation frustrated Emily, particularly as Emily felt that Liz could not physically cope with the demands of caring for Alex and ignored her own health needs as a consequence. Emily implied that this was an attention-seeking method, demonstrated by Liz not eating correctly and then informing the ECE of the fact, in an attempt to imbibe feelings of guilt and pity to secure greater emotional closeness to the ECE (closer relationships), increased frequency of contact from the ECE (visits to see her every day) and increased quality of contact from the ECE (shopping trips instead of a quick cup of tea).

> She's a bit martyrish I suppose…after the seizure Alex was gonna stay in respite care but she was like 'no'. 'No, they won't look after him', and then I'd said to her, 'at the end of the day they are gonna look after him better than you can at the minute' so we sort of like tried to talk her round into it… she tries so hard, because she's said nobody else can look after him…but she can't physically do what he needs. And I get a bit cross with her about that. I think she's a bit of a martyr when she says that.
>
> Emily

Liz cried to Emily and complained of feeling dizzy and ill. When Emily told her to seek medical help, Liz stated she couldn't as she had no one to look after her husband, despite knowing that Emily would be willing. Emily felt anger at the incident and resentful of her attempted manipulation to create pity and guilt. Emily also described Liz using the absence of food as a method to attract attention, similar to Katie's experience with her Mother in law.

> So it was like 3 O'clock… and she said, 'oh I've only had a banana all day, I'm ready for my dinner' and I was like, 'why have you only had a banana all day?' That's mad. I'm just like... it drives me mad!
>
> [Researcher] Why do you think she told you that?

> I don't know. Because she knows that we'll complain at her all the time if she tells us, so I don't know why she did. You have to wonder!… she rings us, she's like, 'oh I've had a rubbish day, Alex's been poorly, I've been crying all day'. And every time, like Richard says, every time we go she says she's had the worst day in the world. It's the guilt trip again.
>
> [Researcher] So how does Richard take that? Does he feel guilty?
>
> Well he doesn't like it. I don't think he does feel guilty, I think he gets annoyed with it because in his mind he's doing what he can. And there's nobody else. We can't share the load, there's nobody else to share it.
>
> Emily

Emily also suggested that Liz felt some level of guilt regarding the care she provided for Alex and so sought approval from the ECE to lessen her emotional burden. A pact had been made between Liz and Alex many years before, confirming that they would care for each other in ill health. Emily suspected that in Liz's eyes, the pursuance of formal caring assistance would suggest to the remainder of the ECE that Liz was negating this promise. Emily believed that because of this, Liz went out of her way to ensure the ECE were aware of her suffering, reminding them at every opportunity of how unhappy she was with her caring identity so that the suggestion of formal help would be initiated by the ECE members and not Liz herself. In this way, Liz got to keep her promise to Alex, but also secured assistance with her caring tasks - the securing of formal caring help was emotionally and socially sanctioned by the ECE.

> She has to come to her own decision, but like I say, with the sit-in service, that was me sort of saying, you're gonna have to look into it otherwise you're gonna go mad. But I don't know whether she'll do it then because she thinks we're OK with her doing it, because if she does it off her own back is she giving up/ Would we think less of her? - If we say it, is it that we are giving her permission to get help? that sort of thing. She feels so guilty leaving him. Because they made a pact that they'd look after each other. Which I get, but she's only physically capable of doing what she can do isn't she. So I guess we have to be the ones to say these things to her, so she knows it's OK.
>
> Emily

Liz was concerned that to seek outside help without the blessing from the ECE may result in tensions between them, that emotional distance in the ECE would be the result. Her self-identity as a carer was not in question, but emotional distance in the ECE was, and as a result changes in her carer role (by incorporating formal help) had to be authorised by the ECE.

4.2. Summary

The findings of this research have identified a number important factors in the provision of informal care for elderly relatives.

Data revealed that distance is a concept experienced by carers which can be geographical/physical, social, psychological or emotional. All concepts of distance were found to be inter-related and changes to the distance in one concept may also result in changes in another. Depending on individual circumstances, the participants revealed that they wished to alter the level of distance they felt in one or more of the distance concepts

The carer self-identity was adopted by degrees – changes to carer identity occurred through a transitional process. There existed a transference of identity in carer participants whereby previous lifestyle, roles, responsibilities and relationships grew increasingly faint, to be gradually replaced with a new carer identity. However, it was also possible to transition identity back towards the identity occupied prior to caring when certain features were implemented. Motivations for the provision of care and its' associated changes to identity were recognised as feeling of duty, obligation, love, affection and reciprocity. In fact, rarely did participants divulge a single motivation for caring for an elderly relative. The different motivations participants shared influenced how, and to what level the carer identity was embraced, or whether the carer role was absorbed into an existing identity. Motivation for the provision of the caring role was often obligation to the care recipient, however, on occasion this obligation was felt to another member of the ECE and not the care recipient themselves.

Some participants desired an increase in emotional distance between themselves and their caring identity. Motivations for this change in distance included feelings of being trapped by the carer identity, feeling that the carers needs had been eclipsed by those of the care recipient and lack of 'me time'. Although more rare, some participants desired a decrease in distance between themselves and their caring identity and again, used emotional distance to manage the change. On occasion, carers were observed to desire full transition to the identity of carer. The level of adoption of the carer identity was not reflected in the same level of increased emotional proximity between the ECE

and was sometimes motivated by a sense of pious embrace in a self-less existence.

Participants also struggled to balance multiple identities or combine identities together and used the manipulation of emotional distance as a method doing so. Changes to self-identity in the carer participants also affected other family members, often due to divided loyalties, level of involvement and restrictions on resources such as free time.

Possessions, rituals, guilt, small scale deceptions and martyrdom were used by participants to alter emotional distance, reinforcing the new carer identity, or previous life identity, depending on individual contexts and the changes desired. New rituals and possessions were acquired by some participants which reinforced their new caring identity whilst the loss of previous possessions and rituals were a source of great distress for others. Some participants attempted to transfer the emotional value of rituals and possessions into new settings, however this was not always successful and the intrinsic value of the possession often became lost when attempted. Possessions were often used in conjunction with altered rituals – the renegotiation of activities that allowed emotional proximity to former identity for both carers and care recipients, which also assisted in producing emotional proximity between those involved in the renegotiated ritual.

Changes in identity often brought about changes in the personalities of the carers and included increased anger and temper, bitterness and depression, but on occasion the changes were positive, such as increased freedom and personal power. Identity changes also caused changes to relationship labels between the carer and cared for, for example husband and wife became carer and cared for – which was described by participants as the hardest and saddest change in identity.

Self-identity changes in carers from their previous identity to that of carer occurred as a process of transition. The caring role can sometimes be absorbed into previous identities however becomes a greater proportion of identity as the carer role develops until complete carer identity is achieved. Emotional distance assists in the transitions between previous identity and carer identity and can be used to inspire transition in either direction.

Table 2 below demonstrates the key themes this research has identified, the evidence supporting the themes and the participants to whom the evidence was based upon (Where C is the carer and CR the care recipient.

Table 2 - Key Themes of Findings

Theme	Premise	Participants	Supporting Statements
Needs of C overshadowed by CR	Health needs	Bob, Carol, Gary, Tracy, Vivienne	*" I am not allowed to be sick or feel like staying in bed for an extra hour or so because I am expected to be at their beck and call - no one gives any thought to how I might be feeling"* – Tracy
	'Me time'	Bob, Carol, Ken, Tracy	*"I feel as if there is no free time for myself and that no one appreciates the efforts I make. Sometimes I barely do cope"* – Carol
	Lack of acknowledgement of sacrifices	Carol, Francine, Gary, Margaret, Tracy	*"I think it would be nice sometimes to be able to just, you know, not do it all…like he says to me, I don't know what you want to go on about caring for, all you ever do is an hour in the morning and half an hour at night, that's the way he sees it you see!"* – Francine
Transition of identity from previous to C	Tensions within ECE	Chris, Edward, Emily, Ian, Jayne, Karen, Katie, Margaret, Neil	*"I have tested my wife more than I should have. We have had many a 'last chance'"* - Neil
	C identity unwanted	Bob, Carol, Emily, Francine Gary, Gwen, Harold, Ken, Tim, Tracy, William, Yvonne	*"I could have very easily have driven my car into a tree most mornings"* - Gary
	C identity wanted	Jayne, Jill, Neil,	*"I don't mind, I don't feel no pressure…I don't feel obligated, my family have always done everything they can for me, I do whatever I can for them. I've never felt obliged to my*

			parents at all. I just feel like I should do it, but not that I have to do it. I want to do it." - Jill
	Character changes	Carol, Gary, Harold, Tim, Tracy, William, Yvonne	*"I barely do cope and have discovered at nearly 70 years old that I have a bad temper. I never thought I had. I was always laid back and happy"* – Carol
	Trapped, no escape	Carol, Gary, Ken, Tim, Tracy, William,	*"Life gets very frustrating at times. You get a feeling of being trapped in a situation you can do nothing about, sometimes you just want to cry or give up but you can't. And yes you can think suicidal thoughts at times and even wish your partner would die so you can actually have a life."* – William
	New roles and responsibilities	Bob, Catherine, Francine, Ken, William	*"All responsibilities are now for me to do, including washing and dressing my wife as well as taking her to toilet, also cooking, shopping etc. Life gets very frustrating at times"* – William
	Decision-making	Catherine, Diane, Edward, Francine, Ian, Karen, Katie, Robert	*"I did. I made it. I was the one that said, if you don't do it now, you'll never do it… because he's never made decisions like that before"* - Karen
	Loneliness and isolation	Carol, Neil, Susan, Tracy, William	*"It's easy as well to feel so alone, not getting much support from family or friends as they could not manage my wife on their own"* – William
	Relationship label changes	Ashleigh, Carol, Susan, Tracy, Yvonne,	*"My feelings towards my husband are now that of a carer and at times I feel like I am living with a child and not*

			someone I used to be able to talk to and discuss day to day problems with. We are not 'husband and wife' now" – Tracy
Deception, Guilt and Threats	Invoke emotional proximity	Edward, Emily, Ian, Jayne, Karen, Katie	*"It's like when we went on holiday it was awful because we'd ring her and she'd be like when are you coming home? And she knew when we were coming home, but it made us feel awful. Putting pressure on. I have seen a change in that sort of thing. It's like the old person, guilt isn't it. She lays it on, makes us feel guilty"* – Emily
	Invoke emotional distance	Catherine	*"I say, since you have to travel, the time with your children is more important, don't feel guilty or anything, we can talk on the phone"* – Catherine
Possessions, Objects and Rituals	Tools for achieving optimal emotional distance	Bob, Catherine, Chris, Dorothy, Francine, Ian, Jayne, Robert,	*"And we even used the wallpaper in here, the same as she'd had in the other house… I went back and we got the same wallpaper, so that was the same… same layout as her house. So we tried to keep everything as emotionally undisruptive as possible."* – Jayne
	Links to previous identity	Ashleigh, Bob, Catherine, Dorothy, Francine, Ian	*"We had a caravan, well we still have one, it's been parked up and not used because Sylvia can't get in and out of it really. I keep saying we are gonna sell it but we never just get round to selling it… It was freedom, to go where we wanted to go, when we wanted it. That's probably why we haven't sold it. We keep saying, but we never do anything seriously about selling it."* - Bob
Motivators for change in identity	Love and affection	Catherine, Chris, Diane, Dorothy, Edward, Gary, Gwen, Harold, Ian, Jill,	*"I would not change a thing, even though it is hard work looking after her. She is my whole life."* - Harold

		John, Karen, Neil, Tim, Yvonne	
	Duty, obligation and moral code	Ashleigh, Bob, Emily, Francine, Fred, Gwen, Ken, Jayne, Jill, Katie, Neil, Vivienne, Yvonne	*"It's an admission that'll resonate with many people caring unexpectedly for loved one. We never chose to be in this position and we certainly never trained for it, yet here we are, unable through our moral consciences or love to do anything other than care."* – Yvonne
	Piety, self-sacrifice and martyrdom	Emily, Jayne, Katie, Neil	*"So many come out with "I don't know how you do it" or "I couldn't do it". One woman in the village asking about Mum ending the conversation with the parting shot "...ruining your life". I have the completely opposite view - how can you not do it?... In the real world, "How's your Mum?" is as much as you get before they glaze over and rush off. My guess is embarrassment from recognising they don't want to do the same. Their willingness to offer excuses kind of gives it away."* – Neil

Findings have indicated an inextricable link between emotional distance and carer identity, however have also shown that re-negotiation of self-identity to the carer identity does not necessarily correspond with increased emotional proximity between those involved and vice versa.

Chapter 5 considers the findings of this research and applies to what is already known about carer identities and their transition. The chapter identifies important and exciting new theories regarding informal care identities and develops a conceptual framework to explain the process of identity transition in informal carers.

Chapter 5. Discussion

5.4.2   Worked example

5.4.3   The transient nature of the carer identity

5.1. Contributions of the research to existing literature

This discussion chapter is centred on understanding how individuals transition from their previous identity to that of an informal carer. The findings have provided valuable evidence as to how and why these transitions occur and a conceptual model depicting such transitions has been formulated.

Utilising extant literature, this chapter describes what literature is supported by this research and what original contribution to new knowledge has been made. The chapter then reiterates the aims and objectives of this research and demonstrates how they have been met. The chapter then identifies and describes a conceptual framework which supports the research aim and provides a worked example, directly from this research, providing an original contribution to existing knowledge on caring.

5.1.1. Elderly care – the current picture

The first section of the literature review demonstrated that there are issues with the current level of care provision from both formal and informal sources, with regards to the number of individuals requiring some level of care. Life expectancy in the UK is increasing and with it, prevalence of chronic disease (Cracknell, 2010; PHE, 2016). Health and Social care budgets are failing to keep pace with spiralling health and social care costs and yet there remains a significant gap between the number of people needing care, and those available to provide this care, both formally and informally (Szinovacz and Davey, 2007). This was supported by this research in that in almost all ECE's considered, formal care options were either absent or inadequate and required some provision of informal care as a sole provider of care, or as a provider of top up care. For some individuals, this led to feelings of bitterness and resentment towards Government, and of feeling abandoned by the formal care system. Reasons behind this shortfall in care provision have been considered and Tolkacheva et al., (2014) suggested that this was because of declining rates of

offspring in families, and hence fewer children to provide care to elderly parents, increasing divorce rates and hence fewer spouses to provide care (Gans et al., 2013) and changes in family demographics and geographical spread (Gilleard and Higgs, 2005). These suggestions were also supported in part by the findings of this research. Certainly for Catherine, the geographic spread of her children meant she needed an alternative source of care which took the form of her neighbour Margaret. For Catherine, geographical distance did not translate into emotional distance and her children kept their previous identities intact – the addition of care from other sources stopped the transition of their self-identities towards that of carer. For Ken, Bob and many other participants, the complete absence of offspring led to them being the sole carer for their wife or husband, particularly as their financial status meant that they were not entitled to assistance with care costs or any provision of formal care input. Findings from this research however did not support divorce as a suggestion for decreased carer availability – indeed all participants in the research were either married, or widowed and so any potential differences in participants exposed to divorce were not considered.

Researchers struggled to define caring, admitting that 'carer' and 'caring role' were relatively new terms and that therefore, the carer identity was difficult to define (Arber and Ginn, 1990; Leira, 1994; Thomas, 1993). This was supported by the theory that the label 'carer' was actually self-identified and was not always recognised as applying to them by the carer. Indeed some carers view their caring tasks as no more than an addition to the existing role and not a shift in their self-identity (O'Connor, 2007) – an opinion supported in this research by participants such as Neil and Emily who confirmed that their caring role was what you do for family members with increasing age and infirmity.

Even the definition of elderly and old age were to some extent, an interpretation in the literature and varied considerably according to the country of consideration. For the World Health Organization, 'old age' was defined as over 60 years, whereas for British retirement purposes, the age considered 'old' was over 65. Age can be viewed as an empirical number, whereas the process of 'ageing' may be seen as an interpretation of the loss of biological and social function and the ability to produce a livelihood (Heslop and Gorman, 2002).

Consideration of empirical age was addressed by participants and was found to be a concern in itself to some. Ashleigh expressed concern at her own increasing age and the ability she had to care for elderly parents in the future as she herself aged. Of greater concern to participants was their own interpretation of 'ageing', not their age – i.e. the decline of their own mental and physical abilities whilst carrying the expectation and obligation to provide care for others. This supports Hubert and Hollins' (2000) call for future research to consider the joint and individual needs of elderly carers and their elderly care recipients.

Although research has been undertaken to understand differences in caring arrangements according to social, economic, religious and ethnic statuses, so far there has been a failure to reach concurrence in extant literature. Laditka and Laditka, (2000) theorised that more affluent children were more likely to purchase care provision than provide it themselves. This was in part, supported by the findings in this research. By far the most affluent ECE was that of Catherine and her children were also very affluent and geographically spread. This ECE did indeed purchase care rather than provide it themselves as they also had successful careers to pursue – an excuse not to provide care readily accepted by all members of the ECE because the family identity and the self-identities within it valued employment as a conduit for identity far higher than that of carer on any level (ECE family members did not provide any care to their Mother). However, in all other ECE's the majority of care provided was unpaid and provided by family members The majority of the participants were of middle-socioeconomic class and working class (Socioeconomic class in this thesis is informed by the interaction between an individual's social, cultural and economic background, (Rubin et al., 2014)). This does not support Hanson, Sauer and Seelbach's (1983) suggestion that less affluent adult children provide less care to family members due to limited resources with which to do so and supports Arber and Ginn, (1992) who suggest that the working classes provide more care than other classes, despite having limited resources with which to do so. This is because the resources related to care include aspects unconnected to financial status, such as time available, love and affection for the care recipient etc.

The body of literature also demonstrated conflicting opinions on the provision of care and its relation to ethnic origin. The respondents of this research were all white, British nationals and so conclusions drawn on the basis of ethnic origin are not possible.

5.1.2. Who are carers?

Much research has been conducted on filial care relationships – that is care provided to elderly parents by their own offspring (Checkovich and Stern, 2002; Leinonen, 2011; Tolkacheva et al., 2014) However Horowitz, (1985) suggested that care is most often provided by the spouse in the first instance, until the needs of the care recipient increase to such a degree to need further input, or the health of the caring spouse begins to decline.

Leinonen, (2011) conceptualised filial caregivers into three distinct categories – *"togetherness"* whereby care is provided equally between siblings, *"back-up"* whereby one sibling takes a lead role in caring whilst others only become involved if the chief sibling is indisposed, and *"absent"* whereby at least one sibling provides no care at all. This concept was supported by the author's research in that all participating ECE's fell into one of these categories. Robert's ECE worked in *"togetherness"* to take the lead on different aspects of Roberts care, from Edward and Karen assessing Roberts living environment and general health and acting as transportation; Chris acting as daily 'check-in' to assess Roberts physical and mental needs on a daily basis and Diane acting as centre of communications, ensuring all ECE members were kept in the loop. For Jill, the division of care for their elderly parents acted in the *"back-up"* concept, whereby Jill provided all care on a normal basis, but with her brother as back-up to provide care when she went on holiday or was ill. For Jayne, disagreements with her sister meant she operated in the *"absence"* concept, regardless of whether her Mother was in agreement with the ECE structure, providing all care whilst her sister provided none (and was prevented by Jayne from doing so, even if she wished.)

Margaret considered her identity as both caregiver and friend and struggled on occasion to classify herself as one or the other. Her paid status led her to believe she occupied the role of a formal carer. She undertook caring tasks and

was financially recompensed. However, Margaret al.so admitted that she did far more for Catherine than she was actually paid to do. Margaret took Catherine to visit her husband at least once a week and was never recompensed for either petrol or her time. She felt unable to raise this with Catherine for fear of offending her, but uncomfortable with the arrangement which led her to deceive her husband by implying that she did indeed receive payment for these visits. This ambiguity of the carer role was highlighted by Barnhart et al., (2014) who also found that there were confusions in carer identities and that on occasion individuals occupied dual roles – at times acting as paid caregivers and at others as a member of the caring family.

Extant research has been unable to form an opinion regarding whether filial care is actually more often provided by a single sibling or through shared care arrangements (Checkovich and Stern, 2002; Leinonen, 2011; Tolkacheva et al., 2014). Certainly in this research, most care was provided by spouses and filial care provided was mainly from both the 'back-up' and 'absent' participation patterns identified in Leinonen's (2011) study. Leinonen's (2011) study was also supported by this research in two other distinct ways. Firstly, Leinonen, (2011) suggested that siblings self-identified as the main or lead carer in the filial care relationship and secondly, that working arrangements had a major effect on an individual's availability for filial caring. For Jayne, the self-identity label of carer was of extreme importance and not to be shared with her siblings at any cost. The carer role had great emotional value in terms of her own perceived duty and obligations and she had redesigned her life and identity around her role of carer. Jill however, felt that as the eldest daughter, it was her duty to be lead carer but also felt that as her brother worked full time and herself only part time, this was a good reason for him to only provide back-up care. Indeed, research has been instrumental in highlighting the plight of carers who also balance work commitments (Checkovich and Stern, 2002; Leinonen, 2011; Seay, 2010; Tolkacheva et al., 2014,) although this was not highlighted as a particular issue by this research, potentially because the majority of the carers included in this research had already terminated paid employment and of those remaining in work, very few were in full time employment.

It is well documented that care for family members is primarily provided by females in the family (Campbell and Martin-Matthews, 2003; Collay, 2002; Dwyer and Coward, 1991; Finley, 1989; Horowitz, 1989; Laditka and Laditka, 2000; Raschick and Ingersoll-Dayton, 2004; Seay, 2010; Stoller, 1983) yet this was not supported by the author's research whereby almost half of participating carers were male. Of the male participants in the research, most were spousal carers and few were adult child carers. This differs from the females included in the research whereby around half were spousal carers, a few were adult child carers and the remaining participants were other family members providing care, including daughter in laws, sister in laws and even neighbours. This refutes the claim made by Allen et al., (2012) who suggested that care is only provided by the wider family members in exceptional circumstances. Admittedly however, the population studied was small and the research not designed to examine carer demographics. Nonetheless, inclusion and consideration of gender and role differences are an important consideration in this research because it has associations with self-identity, the management of multi-identities and cultural expectations of care according to gender and familial role.

The existence of gendered caring tasks (that female carers are more likely to provide personal caring tasks such as bathing whereas males are more likely to provide arms-length assistance such as financial management) as suggested by Campbell and Martin-Matthews, (2003), Dwyer and Coward, (1991), Horowitz, (1985), Laditka and Laditka, (2000) and Stoller, (1983) were not evident in the findings of this research. However, the majority of male carers were spouses and the only member of the ECE excluding the care recipient. Interestingly, accounts from Fred and Catherine confirmed that it was their daughters that provided financial management assistance, despite both ECEs containing sons. This does not support the suggestions of Laditka and Laditka, (2000) that male members of an ECE are more likely to provide financial management assistance. Gender boundary taboos as described by Arber and Ginn, (1990), Ekwall, Sivberg and Hallberg, (2004), Campbell and Martin-Matthews, (2003) and Matthews, (1995) (whereby male carers would not complete certain caring tasks due to moral codes and fear of impropriety) were also not supported by this research, which evidenced both male and females conducting personal care tasks equally. However, as discussed above,

participants of this research were largely spousal carers with no other ECE member providing informal care and so perhaps gendered care tasks did not exist from necessity of the care situation.

In most extant research it is believed that the female caregiver (as opposed to male caregivers) experiences more negative consequences of caring such as feelings of depression, conflict and anxiety and stress (Horowitz, 1985; Raschick and Ingersoll-Dayton, 2004; Neal et al., 1997; Walker et al., 1995; Yee and Schulz, 2000) however, this claim was also unsupported in this specific research and almost all participants revealed negative consequences of caring, from feelings of frustration (Ken, Edward, Emily and Jill) to severe mental health issues and even suicide ideation (William, Gary, Carol and Tracy) with no gender differences.

Unlike research conducted by Stoller, (1983), Bracke et al., (2008) and Laditka and Laditka, (2000) regarding the effects of marriage on caring, all son and daughter participants of this research project were married, suggesting that marital status is less use as a predictor of the intention to provide care than previously found. However, this could be incidental to participant inclusion in this study.

5.1.3. What affects carers?

Tensions result from the caring relationship and involve other family members who may or may not be involved in direct care (Dean et al., 2014; Johnson and Spence, 1982). This is exacerbated by a generational overlap in those requiring care resulting from increased life expectancy and a prolonged period of adolescence (Gans et al., 2013; Skolnick and Skolnick, 2003). These tensions were common in the findings of this research and competing demand for carers time a common source of these tensions. For Edward, tensions around the caring role he provided for his Father were frequent and involved his wife Karen and their two children. Edward felt divided in his role, describing himself as a tree that everyone expected to take a branch from, essentially experiencing conflicting self-identities which he struggled to reconcile. The tensions often terminated in arguments with Karen and created emotional distance between the two and the familial unit. This was exacerbated by Karen's frustrated

perception that Edward's brother Chris was not fulfilling his caring duty, and that geographical distance between Chris and their care recipient Robert was not a good enough excuse – Karen felt her brother-in-law Chris should accept the caring identity to a greater extent than she felt he did. The competing demands of different identities experienced by Edward created emotional distance between himself and his wife and also between himself and his own young sons (as he missed their Sunday football matches to care for his Father etc.) A similar experience was had by Emily and her husband who also had two young sons. Emily and her family were expected to attend Liz's house each weekend to provide care and companionship and Emily described these visits as problematic as her sons became bored and misbehaved and wanted to do other things at the weekend besides sit at Granny's. The result was increased arguments between Emily and her husband, creating emotional distance in the marriage which wasn't present prior to the caring role. Emily considered her caring role a duty or chore that she resented having to perform, which increased emotional distance between herself and her Mother in law. This was exacerbated by the cared-for Liz, attempting to minimise emotional distance in the group and secure a greater emphasis on the caring identity from her ECE. In fact, Liz's attempts to decrease emotional distance in the ECE through her insistence of increased frequency and duration of contacts had the opposite effect of increasing emotional distance in the group, and resentment of the caring identity being forced upon them (in particular Emily). This resulted in no change in identity of those involved and only the addition of the caring role as an extra duty to be performed under duress.

The idea of reciprocity in caring has been investigated in a number of studies (Bengtson and Roberts, 1991; Caputo, 2002; Silverstein et al., 2002) and exchange theory was also found to be present in the findings of this research. For Jill, motivation to provide care for her elderly parents stemmed from feelings of reciprocity. She stated clearly the proviso that 'they did for me, now I do for them' however, was the only participant to allude to reciprocity as a motivator for the caring role. Reciprocity must be based on an understanding and appreciation of the care provided to the adult child during childhood (care including both direct care, but also other aspects such as financial support). If this is not present, reciprocity cannot exist (Silverstein et al., 2002). Other

participants such as Jayne revealed the opposite of Jill's sentiment by stating that her Mother for whom she now provides care was *"not a good Mother"* whilst she was young and suggested that the care she now provides was not out of a sense of reciprocity, but out of a sense of duty to her now deceased Father (who had previously always cared for her Mother). The data of this research therefore suggests that reciprocity as a motivator for informal caring can only exist when emotional proximity exists between the actors, but primarily, motivations to provide care are borne from duty, obligation and genuine affection, supporting the findings of Leinonen, (2011).

The first objective of this thesis was to understand the impact of distance on caring relationships and identities; the second, to understand the transitional process associated with self-identity when informal care provision commences. The remainder of this chapter will focus on clear explanation and achievement of the specified objectives through the evidence of this research and supported by the body of knowledge already known.

5.2. Objective 1 – Understand the impact of distance on informal care identities and relationships

The first aim of this thesis was to understand the impact of distance on informal care identities and their inter-relationships. The research identified four types of distance; geographical/physical; social; psychological; emotional. However, all the concepts of distance identified were found to be inter-related with a change in one concept potentially resulting in a change in another. Emotional distance in particular was found to affect, and to be affected by all other concepts of distance. The data sources were very rich in providing details to each of the distance types identified, however, the restrictions on the production of this thesis (time constraints, word count limitations etc.) meant that all four concepts of distance could not be covered in full in this thesis. To that end, a brief description has been included of each, but the main discussion has centred on the examination of emotional distance and how it affects self-identity, as it is this type of distance that may primarily have the greatest effect on caring identity transitions and therefore links both objectives of this research together.

5.2.1. Geographical Distance

Geographical distance is the actual distance, in metres, between the carer and cared for, or carer and services etc. This can be great, when families live some distance from each other, or can be small, when carer and cared for co-reside. Local shops may help minimise actual distance between ECEs and amenities (ILC, 2013), whilst living in very rural areas often relates to high geographical distance between individuals and other people and services (Gilleard and Higgs, 2005). Proximity of the ECE to the cared for can be advantageous for both the carer and cared for as it is often the members of the ECE that are geographically closest to the cared for that take a lead role in the provision of care (Checkovich and Stern, 2002; Leinonen, 2011). Geographical distance on the caring relationship has been considered in the body of literature (Campbell and Martin-Matthews, 2003; Hamon, 1992; Lawton et al., 1994). Lawton et al., (1994) hypothesised that geographical proximity was inextricably linked to emotional intimacy and that the quality of the caring relationship was built on the strength of intimacy between carer and cared for. This was supported by

Campbell and Martin-Matthews, (2003) who also concluded that geographic proximity was a valuable predictor of the provision of care provided through filial relationships, surmising that geographic proximity led to increased carer involvement. This research supports this assumption in the cases of Jayne and Jill. For Jayne, who moved her Mother from one end of the city to the other to be closer to her (against her Mother's will), geographical proximity was paramount to frequency of care involvement and in her mind, frequency of care was directly related to quality of care and emotional intimacy. Similarly Jill lived within a few streets of her elderly parent and would not consider moving away, even for a better job. For Jill, quality care could only be provided with geographic proximity – being able to *"pop round"* to check on them and to be able to get to them quickly in the case of an emergency.

Data revealed an optimal distance which suited the participants' present circumstances but often implied that this distance would change if circumstances changed also. The value of geographical proximity seems to be of particular importance in times of crisis, when an action response is required of the ECE. For Ian, this was important when his wife became ill and resulted in his children being named responders in the 'lifeline' system (an emergency button worn around the neck by vulnerable people in case of an emergency).Their geographical proximity allowed them to respond quickly to a sudden change in need of the care recipient, but also in their ability to provide follow up support through increased frequency of contacts. For Ian's ECE, geographical proximity allowed the carer role to be shared throughout the group, keeping invasion of the caring role minimal to any one individual and hence, necessitating minimal change in the self-identity of those involved. In Ian's case, geographical proximity led to reassurance and enhanced emotional closeness between the ECE.

As previously stated, the data demonstrated an optimal physical distance between carers and their care recipients. Unlike the case of Ian described above, some participants did not wish to be too physically close to their care recipient as this suggested a greater expectation for increased frequency of contacts of their care recipient – the participants showed concern that whilst they were happy to provide care, they did not wish to provide all care, all of the

time. This suggests that an optimum geographical distance relates to an optimum uptake or transition to the carer identity which is different for each individual. Likewise, care recipients had optimum geographical distances between themselves and their informal carers – some participants were concerned about invasion of privacy, interference and loss of autonomy when carers were geographically close. This supports Hamon, (1992) in the theory of an ideal distance between those involved in informal carer relationships. Interestingly, none of the care recipient participants desired closer geographical proximity to their carer. Again, this suggests that there may be an optimum uptake of the care recipient identity as well as the carer identity which supports O'Connor, (2007) in that the inception of the carer identity means a corresponding transition for the cared-for to the care recipient identity and also supports Broady, (2017) in that the transition to care identities can become central to understanding self and familial roles and identities for all involved. This also supported Gilleard and Higgs, (2005) who suggested that increased geographical distance in caring relationships resulted in fewer changes to the carers' everyday life in response to the inception of informal care. This then meant that caring identity transitions were avoided or delayed.

Differences in geographical proximity between ECE members were shown to relate to differences in communication methods. The greater the physical distance between carer and cared-for, the greater the reliance on remote contact methods such as the telephone. The data revealed that the perceived quality of remote contacts were less than actual face to face contacts, although Gilleard and Higgs, (2005) suggested that changes in kinship have resulted in less emphasis on face to face contacts. Data confirmed that participants demonstrated this perceived reduction in quality by increasing the frequency of contacts in ECEs with greater geographical distance in an effort to ensure emotional closeness and highlight their commitment to the care recipient, despite the miles between them. Face to face contacts were far less frequent in ECEs with geographical proximity than remote contacts in ECEs with geographical distance, despite Lawton et al.'s (1994) claim that increased geographical proximity encourages emotional intimacy in family relationships and Campbell and Martin-Matthews, (2003) claim that geographical distance can be used as a predictor of care involvement.

The findings demonstrated that even when geographical distance between ECE members was minimal, carers confirmed a need for increased physical distance at times, specifically through the use of holidays to provide a break from their caring duties but also revealed practical problems associated with this (such as lack of another carer to stand-in) and also emotional problems with taking a break from the carer role (this is discussed more fully in the emotional distance section). The findings confirm the importance of carer breaks on burden perception which supports research by Stephens and Franks, (1999).

The findings suggested that the driving force for increased geographical proximity between ECE members was sometimes the carer themselves. One carer participant admitted to pushing her Mother into moving closer to her so that she could provide increased levels of care, via threats of withdrawing care altogether if her wishes were not obeyed. The carer wished to transition her identity to being more fully a carer which required (in the carer's view) increased geographical proximity, despite knowledge that the move would have a severe detrimental effect on the emotional and mental health of her Mother. This supports Gilleard and Higgs, (2005) regarding the importance of ageing in place and the reluctance of the elderly to move homes as their age increases.

This research was originally designed to consider two distinct study groups – those that reside in a rural and urban area. However the findings of this research suggested that the experiences of both study groups were in fact very similar. Increased geographical distance from services and amenities were not highlighted as an issue of great importance by participants. This is in contrast to the claims made by Pei and Tang, (2010) and the ageing project completed by the International Longevity Centre, (2013), who both confirmed that rural carers and care recipients experienced greater challenges than their urban counterparts, but was not supported by the findings of this research. Rural participants did not feel any greater concern regarding access to services compared to those residing in urban regions, nor did they find rural living any kind of barrier to contacts with their ECE. This does not support the work of Creese (2003), Heenan (2008) and Tommis et al. (2007) in that there were no great differences supported by this study between urban and rural residents providing or receiving informal care. This may be due to quality public services,

access to private transport or the abundance of local amenities in the rural villages included in this research. A further potential explanation for the few differences noted is that the rural/urban divide in the two study areas was not of great difference (all participants resided in the same county in England) and greater extremes of urban and rural living would be potentially required for major differences in experiences to be noted. This research has addressed calls (Creese, 2003; Goins et al., 2009; McKenzie et al., 2010; Tommis et al., 2007) for further research into rural and urban differences in caring, and supported Dwyer and Miller's (1990 p.35) suggestion that "*caregiving-related characteristics do not conform to a residential continuum*". This research also supports Goins et al., (2009) and McKenzie et al., (2010) who discovered few or conflicting differences between urban and rural care givers in their literature reviews.

This research identified few urban/rural differences in informal carers, however did identify differences between those that did and did not reside with their care recipient.

The state of co-residence between the carer and cared for was identified as an issue by participants of this research, this essentially being when the physical distance between carer and cared for is very small or even non-existent. Findings suggested that carers who live in the same house as the person they care for suffer increased burden due to the lack of physical distance between them. Tensions between the carer and care recipient were common, often due the carer desiring more personal space and the care recipient wishing to spend more time close to their carer. For some participants the increasing need for physical closeness of their care recipient resulted in frustration and a greater desire to increase that distance, essentially desiring a transition in identity to that before caring took hold. Some participants managed this through carer breaks and holidays (ultimately transitioning their self-identity, enjoying roles and activities enjoyed in a previous identity for a limited and defined period and then transitioning back to the carer identity on their return), supporting findings by Bevans and Sternberg, (2012) regarding the importance of carer breaks; whereas for others this was not an option. The data revealed the importance of the ability for carers to relocate physically within the confines of the shared

house for part of the day, particularly using parts of the house and gardens (such as an upstairs room or garage and even labelling the rooms of the house with ownership tags (e.g. "*Toms room; my room")* in an effort to secure physical distance from their care recipient and allow psychological distance away from their caring role (this is discussed in more detail in the psychological distance section.) The data revealed that one of the most significant and challenging aspects of the caring role is that duties are 24/7 (supported by Chambers et al., 2001) – that carers do not have the luxury of leaving the caring role at the end of the working day and so feel taken over by their caring role, that they have no life of their own and that their own needs are eclipsed by those of the person they are caring for, essentially, carers feel that their self-identity has transitioned fully to that of a carer and they are unhappy and/or discontented with this new identity. Their ability to get some physical distance from their caring situation is severely hindered. In the cohort of participants that co-resided with their care recipient, the use of tools that secured distance were of greater importance than those who did not co-reside. Such tools included the possession of a car (and the ability to drive it), the possession of motability scooters, internal telephones (for communication within the house so carer and cared-for could occupy different floors, yet still be contactable), household CCTV which could be accessed via a smartphone etc. The use of such tools secured geographical distance, but also acted as mechanisms to connect the carer to their former life and identity. Participants also identified the negative effect that co-residence had on other members of the ECE, altering the wider caring relationships and supporting Dooghe, (1992) and Bursack, (2018) in highlighting the need for careful consideration in the decision to co-reside. The research supported Gibson, (1992) in suggesting that carers who co-reside with their care recipient often suffer greater burden than those who do not. This may be due to an associated increase in the actual care provided (Arber and Ginn, 1990), or because they lack the ability and/or opportunities to increase physical distance as readily as their non-coresidential carer counterparts.

A further point identified by the participants was the increased importance of white goods in care relationships in which geographical distance was an issue. The purchase and ownership of items such as a food freezer and microwave oven took on greater importance as they allowed the introduction of arms-length

care. ECE members were able to ensure sufficient supplies of food for their care recipient and the provision of a regular cooked meal without actually having to be with the care recipient to do the cooking. This supports Trees and Dean, (2018) who identified the provision of cooked meals as a method for doing family successfully, essentially allowing the ECE to provide care without the associated transition of self-identity.

5.2.2. Psychological distance

This is the distance experienced through the thoughts of the ECE members, including both the carer and cared for and can be classed as 'mind distance' for differentiation purposes. The findings of this research suggested that individuals often try to increase this type of distance when other forms of distance cannot be increased – particularly physical/geographical distance. For example, Bob and his wife whom he provides care for reside in the same house, but use Sudoku and crosswords to distance themselves psychologically from each other – despite sitting in the same room, their minds are elsewhere.

Participants reported that they were able to use objects, possessions and pastimes to increase or decrease psychological distance from their situation, depending on their own individual circumstances. Although there exists extensive literature regarding carer wellbeing and the psychological impact of caring, surprisingly few studies have been conducted which consider the attainment or avoidance of psychological distance from the caring identity and how objects, possessions and pastimes are used to aid this.

The data demonstrated that possessions and pastimes are used by carers in different ways to increase or decrease psychological distance from the caring role, according to their own individual need. Many possessions described in the data were used as tools to minimise worry – to allow the carers mind to focus on other matters with the safety net of a communication channel available 24/7 (in the case of mobile telephones). In this way, the meaning (or lack of) attached to objects could be covertly manipulated to elicit a certain response (McCracken, 1987), for example, Robert reported family arguments if his mobile phone (a phone purchased by the ECE for Robert, against Robert's wishes) was switched off. The aim of the ECE was to ensure the safety of Robert, but

ultimately it was the threat of arguments and the emotional tension this caused that persuaded Robert to keep the phone switched on, despite Robert having no personal desire to do so. Other possessions acted as distraction aids which could be employed by the carer to keep the cared-for busy for a short period, freeing up the carer mentally. Examples of this included use of the TV, radio and computer. These possessions also acted as instruments in expressing self-identities in both the carer and cared-for, from the TV programme of choice to the ability to shop online. The mental stimulation from these objects and the agency involved in their use was shown to be an expression of self, supporting Belk's (1988) view that possessions can be incorporated into self-identity to create an extended self (Belk, 1988).

Further possessions and activities were employed by carers in direct response to an unwanted change in their self-identity. The hobbies and pastimes previously enjoyed often became lost with the onset of care provision. Re-visiting these hobbies allowed the carer to re-connect with aspects of their previous identity, ultimately halting the progression of their self-identity towards full and complete carer. In fact, the findings of this research confirmed that objects associated with old hobbies, even when no longer used in the pursuance of the hobby held great value for the carer. This supports McCraken, (1987) in confirming that objects become imbued with meaning, act as an aide memoire and provide an important link with past experiences and feelings. In this way, objects associated with previous hobbies (such as the caravan that Bob cannot bring himself to sell) can convey identity to actors (Epp and Price, 2010).

The data also demonstrated the importance of days out for carers such as visiting local landmarks or shopping trips, either with or without their care recipients as a method for managing carer burden and negative consequences of providing care, such as loneliness and isolation (discussed in greater depth later in the chapter). This supports Chambers et al., (2001) who suggested that carer wellbeing was negatively affected by isolation and confinement, confirming the importance of mental stimulation in the form of days out etc. Finch, (2007) also highlighted the importance of maintaining routines and rituals to sustain former self-identities. The findings of this research supported this

suggestion, particularly with regards to routines that include the potential for mental stimulation such as shopping trips. For Francine, continuing the ritual of visiting the local garden centre was of great importance to both her and her husband for whom she cared. The ritual had formed many years ago, and whilst it was now altered, the ritual of the drive and the walk around the centre provided mental stimulation to both parties, but also a topic for further conversation on their return.

Supporting this, the findings identified a strong desire for the carers to give something back to wider society. Psychological stimuli was sought from external (and often new) sources, adding new aspects to the carers self-identity, which were perhaps not even present in their life prior to caring (often because becoming a full time carer resulted in the termination of paid employment), an example of this is Bob taking on the role of local councillor in an effort to contribute to his local community and as an opportunity to use his mind purposely. Carers desired an outlet for the sum of their intellect, knowledge and experiences gained throughout their life-course and so sought new roles and responsibilities which would not impact on their responsibilities as a carer, essentially creating a new self-identity which did not solely revolve around caring. This active seeking out of new intellectual/psychological challenges clearly improved the carer's wellbeing (in their eyes at least) which links to Bevans and Sternberg, (2012) who suggested that carer burden was associated with the carer's perceived necessity to change their lives in ways they had no desire to do so, but also supports Broady, (2017) who confirmed the importance of new aspects in a carer's identity in preparation for the carer identity's termination (such as on the death of the care recipient).

5.2.3. Social Distance

This distance often comprises of all three other forms of distance and 'social' can be classified for the purposes of this research as a social interaction between the carer or cared for and others. This distance can affect other types of distance – for instance, the cared for going to a social club or day centre, gives the carer free time to be able to do their own shopping (physical distance); gives the cared for the opportunity to use their mind to meet new people or try

new activities (psychological distance); and allows the carer to feel that the cared for is less dependent on them and can enjoy activities without them (emotional distance). Social distance can also refer exclusively to the social interactions within the ECE itself – how much they do or don't get involved in caring, how they communicate with each other etc.

The importance of social interactions for carers was not well documented in existing literature, however the findings of this research highlight some important aspects. The data demonstrated envy felt by carers who were unable to pursue social outlets due to the responsibilities of their caring role, as suggested by Chambers et al., (2001). Social distance from friends and acquaintances gained through the pursuit of previous hobbies were apparent and resulted in altered self-identity from both what it was previously, but also from what the individual wished it to be. This distance from the desired self-identity resulted in tensions within the caring relationships, frustration for the carer and general dissatisfaction with the life-course for the carer. Active social lives were found to be an integral part of the carer's interpretation of a normal life. The continuation of some social activities provided carers with a link to their previous identity before the inception of their caring role. However, carers' ability to dovetail their social wants and needs with the complexities of their caring role were difficult. These difficulties resulted in some loss of previous friendships, as time constraints did not allow carers the ability to nurture existing friendships, or find outlets for the development of new friendship, supporting evidence by Carers UK, (2017). This was exacerbated by carers who terminated paid employment to provide informal care full time. Self-identities developed through paid employment were lost and added to this were the loss of potential social interactions developed and maintained through paid employment, such as friends at work, work nights out etc. reinforcing the findings of Barnes et al., (1995)

The data demonstrated that social distance could be increased or decreased through the use of certain possessions. An example of this was Bob who was unable to bring himself to sell the family caravan. Although Bob accepted that the caravan was likely never to be used again and was a drain on financial resources, he was extremely reluctant to sell it. The social identity he

possessed was intertwined with the ownership of the caravan and the loss of one, suggested the loss of the other, reinforcing Belk's (1988) theory of the extended self. Bob was unwilling at that time to acknowledge the transition of his self-identity from its previous position to that of carer in terms of social interaction. The value of the caravan could not therefore be seen in simple monetary terms, but was seen as an accumulation of personal value due to the social and personal interactions that had taken place involving it (Epp and Price, 2010).

Not only did the data demonstrate the important links that possessions had to self-identity, but also the importance of rituals. Rituals play an integral role in making people feel secure (Phipps and Ozanne, 2017) and the continual renegotiation of family ritual is crucial during family transitions (Trees and Dean, 2018; James and Curtis, 2010) and so are of great importance in care relationships, particularly with the inception of the caring role. Of particular significance to social distance was those rituals centred on holidays. Holidays were considered social pursuits by participants that were also reluctantly ceased. Renegotiation of former holiday rituals to allow an altered state of social interaction were seen as important and provided key links to the previous social identity enjoyed by both carer and care recipient alike and provided a form of carer break (from the daily routines associated with caring at home), which is of great importance to the wellbeing of the carer (Carers UK, 2017). However, the acceptance of this renegotiated ritual was sometimes difficult to accept by all of those involved, particularly hoteliers, holiday staff etc. One example of this was Ashleigh and her husband who enjoyed holidays abroad but who had suffered bad experiences with hotels unprepared for customers with her husband's form of disability. The couple felt uncomfortable with highlighting the modifications they required to hotel staff, fearing they would be seen as being difficult and also disappointment that hotel staff rarely addressed her disabled husband directly, preferring to communicate through the proxy of his wife. This supports Clements, (2013 p.398) who reflected on the conceptualisation of individuals with disability as a *"compliant cripple… grateful for the services and sympathies bestowed on him"*. The care recipient also felt that highlighting his additional needs emphasised the differences in the holiday ritual now, as opposed to prior to his illness which he worried, would reduce the enjoyment his wife Ashleigh

got from their trips. Essentially the renegotiation of the holiday ritual and its subsequent reiteration to holiday providers confirmed a transition in his social identity from prior, to after the inception of his caring needs and identity as a care recipient. In this way, renegotiation of old rituals can serve as a tool to decrease distance from prior social identities, but can also inadvertently highlight increased distance from it too, which may ultimately cause sadness and stress. This is because repeated routines and rituals sustain a sense of identity, both self, and shared (Cheal, 2002) but during times of disruption (such as the onset of caring) rituals can serve as tools for adaption and resilience (Mason and Pavia, 2006), or highlight the disruption further when these important rituals are altered.

The findings of this research also confirmed that social distance could also be minimised through addressing issues regarding geographical distance. The data demonstrated that modes of transport were important in allowing participants to actually access social activities. For many this meant the use or moderation of cars and driving rituals, but on occasion, other methods for embarkation were sought. One particular key possession and transportation ritual considered in the data was the use of mobility scooters. Mobility or motor scooters allow the user the freedom to travel short distances unaided and were often used for shopping trips to local shops for grocery provisions, which in turn were opportunities for participants to engage in social activities with friends and neighbours, or even social interaction with shop assistants etc. For some individuals, the renegotiation of the shopping ritual to include travel by motability scooter preserved former social identities, despite no longer being able to drive – Dorothy still went to the local shops and maintained her daily social interactions but now utilised her mobility scooter, rather than her car to do so. This supports Belk's (1988) theory that possessions become part of the extended self, and can act as tools to maintain or alter self-identity – in this case, the emotional distance Dorothy felt from her previous social identity was minimised by her possession (the use of possessions and rituals in altering emotional distance is further discussed later in this chapter). This demonstrates that the concepts of distance identified in this research are actually inter-related, and in this instance, utilising tools to change geographical distance resulted in a

change in the level of social distance experienced and also the level of emotional distance felt from the participants' former identity.

One issue highlighted as of great importance was the carer's ability to engage socially with other carers. The importance of information gathering and the sharing of experiences directly related to caring was emphasised frequently. The significance of carers socialising with other carers was confirmed by Chambers et al., (2001) who acknowledged that carers suffered from anxiety and frustration in their attempts to source information and support, but greatly benefitted from social interaction with other carers. This study also supported the work of Chambers et al., (2001) in identifying carers who desired more formal training in care provision and conduits such as carer groups which meet regularly to share experiences and tips.

5.2.4. Emotional Distance

The objective of this research was to consider the concept of distance and the findings have shown that there is in fact, more than one notion experienced by the participants of this research. The main notions identified were geographical, social, psychological and emotional concepts of distance. Unfortunately due to limitations of time and resource and because of the sheer weight of the findings in this area, only one concept has been considered for the progression of this thesis which is the concept of emotional distance. This is because many of the other concepts interplay with emotional distance – for example, living geographically distant from friends and relatives demonstrates geographical distance, however for the participant, it may be the feeling of isolation and loneliness this geographical distance resulted in which was the main factor in self-identity change. Participants experienced issues relating to social distance from not having time and opportunity to see their friends due to their caring role, but it was actually the emotional connection of friends, the 'me-time' and the ability to share emotional problems that were the key issue for them. The absence of psychological distance was also highlighted as a factor for participants and many used artefacts such as crosswords and Sudoku to attain psychological distance from their care recipient, whilst still occupying the same

room. This allowed participants to emotionally disassociate with their care recipient for the period of time they were psychologically engaged.

Objective 2 and the remainder of this thesis is therefore based on the concept of emotional distance and its relationship with carer identities and their transitions.

5.3. Objective 2 - The transitional process of self-identity in informal care

5.3.1. Motivations for transitions associated with the carer identity

5.3.1.1. Duty and Obligation 'V' Love and affection

The findings demonstrated that the reason(s) that carers chose to provide care could sometimes be an indicator as to what extent the carer was prepared to change their self-identity from their previous role, to that of a carer identity. Data revealed that the most common motivation for providing care was feelings of obligation, duty, moral code or ethical standpoint and religious views. This does not support Leira, (1994) who suggested that motivation for caring must be borne from genuine affection and concern for the care recipient. For many participants who provided spousal caring, the promises they made in their wedding vows *"for better or worse, in sickness and in health"* were the overriding motivation to provide care. Although this was often coupled with feelings of love and genuine affection, this was not always the case. The motivation of 'promises' to provide care between the carer and care recipient often resulted in greater transitions to the carer identity, perhaps because of the moral claim their motivation had on then, supporting Daly, (2002) who explained that the provision of care relied on the ethics and moral orientation of the carer and Engster, (2005) who maintained that caring existed because of a moral obligation to provide care. Because this motivation was more often seen in spousal carers, the carers were more likely to be co-residing with the care recipient – a group which transitioned more fully to the carer identity than other carer groups, such as filial carers, supporting Allen et al., (2012) who also found that spouses were more suitably placed for the role of carer. For some carers motivated to change identity on the basis of duty and obligation however, there existed discontent – the reality of the situation was not considered at the time those promises were made. Statements such as "*had I but known what this would mean in the future"* were common, suggesting that the carer identity transition was not welcomed, expected or planned. Indeed the data revealed carers with the viewpoint that the making of the promise to provide care and the obligation felt to uphold it had a significant *"cost"* to the carer – ultimately the

loss of their previous self-identity and its replacement with an unwanted carer identity. Rindfleish, (2005) suggested that individuals in identity transition may adopt a *"spiritual supermarket"* approach to religious or moral promises made prior to transition, essentially pick and choosing which parts they wish to transition to their new self-identity but this was not supported by this research. Bevans and Sternberg, (2012) identified caring as stressful, dynamic and unrelenting and yet moral obligations made prior to informal care commencement were sustained during identity transition. The findings also supported Baikie, (2002) in that many spousal carers felt guilt in admitting they were unhappy with their caring role in that such an admission could be construed as a failure to fulfil their marital vows or *"letting their partner down"* (Baikie, 2002 p.296).

The findings also revealed that the extent to which self-identity transitioned to a carer identity was linked to the infirmity of the care recipient, supporting research by Checkovich and Stern, (2002). Whilst care recipients were relatively well, the self-identity of the carer was able to retain aspects of that carers' previous life, but gradually transitioned over time as the health of the cared-for declined, until such a time when the transition was complete, the carers' old identity was lost and replaced with the carer identity. Occasionally, the transition occurred abruptly due to an unexpected health implication, such as the cared-for suffering a major health crisis such as a stroke. This catapulted the carer away from their old identity and towards the carer identity much quicker, however even after such an event, there was usually continued, gradual further transition as the care recipients' health did not usually remain static and inevitably got worse, not better. This transition created emotional distance for the carer from their previous identity – borne from the motivations of obligation and duty. This theory did not support the findings of Gooberman-Hill and Ebrahim, (2006) who found that carers coped better with sudden onset of health implications such as strokes. They argued that sudden onset health events often allowed prognoses that included the implications of health improvements, which provided greater motivations for carers and a more positive outlook directed at recovery and not management of the status-quo. This was not found in the confines of this research.

Further examples of duty as the motivator to provide care and transition self-identity were also seen in other family members who provided care. The data revealed this most frequently in daughter-in-laws who provided care. The motivation to provide care was borne from a sense of duty towards their spouse, not the care recipient themselves. As a result of this, less affection and love were seen towards the care recipient and the complete transition to carer identity was not seen in the data. The findings demonstrated that in certain ECEs, family members other than spouses and adult children are the primary carer. This does not support the findings of Allen et al., (2012) who advised that other relatives were unlikely to provide informal care. The findings suggest that motivations which do not include the actual care recipient results in a limited transition to the carer identity, and the limited transition that occurs is generally resented and unwelcome. In fact, the findings revealed that duty felt towards another member of the ECE and not the care recipient can result in the deterioration of the carer-care recipient relationship; emotional distance between the cared-for and their carer may increase to such an extent that carers refuse to transition their self-identity at all; active dislike of the care recipient replaces previous relationships positions and the resulting tension increases emotional distance between other members of the ECE also.

The findings also revealed that illness was regarded differently by ECE members and affected their willingness for identity transition. One participant in particular found the duty and obligation to care for his Mother who suffered from dementia especially difficult. He resented the change to his self-identity and felt no love for his Mother. His Mother was then diagnosed with cancer and the love he felt *"came flooding back"*. His ability or desire to transition his self-identity was different when his care recipient suffered a physical ailment, rather than a mental condition, despite the dementia continuing and the cancer causing no symptoms (and so no behavioural change in the care recipient). This supports findings by Schofield et al., (1998) who found that carers of individuals with physical impairment exhibit less burden and resentment of the caring role than those caring for individuals with mental impairment.

Sense of duty was also attached to familial roles, in particular the obligations attached to the eldest daughter role. The findings revealed that frequently,

eldest daughters took greater responsibility and action in caring for their parent(s), were willing to transition their self-identity to a greater degree, and that this expectation was viewed as normal with the remainder of the ECE and society in general. These findings regarding eldest daughters concur with Caputo's (2002) finding whereby societal norms necessitate the heightened responsibility of eldest daughters in caring relationships. In conjunction with this, reciprocity was also a common theme in motivations to provide care by eldest daughters in that they were motivated to transition their identity because of the care and assistance they received from their parents in earlier years – a motivation not often found in ECE members not occupying the eldest daughter role. The findings of this research regarding reciprocity support findings by Bengtson and Roberts, (1991), Raschick and Ingersoll-Dayton, (2004) and Silverstein et al., (2002) in that caring may be provided as payback for time and financial investments made throughout the life-course of the adult child. The findings suggested that societal norms in the study areas were that eldest daughters were expected to take the lead in caring for elderly parents, act as centre of communications about their elderly parents with the remainder of the ECE, orchestrate all aspects of care and act as gatekeeper to other ECE member involvement. This supports findings by Bracke et al., (2008) who identified the notion of one family member (usually female) controlling access for other family members, directing the level of care and specifying the caring tasks that other members of the ECE are allowed, or not allowed to do.

The data revealed that primarily, a sense of duty and obligation were motivating factors for the provision of informal care and identity transitions towards that of carer. Although sometimes exclusive, for many participants, feelings of obligation were intertwined with feelings of affection and love, either directly for the care recipient or for other members of the ECE.

5.3.1.2. Desire to increase emotional distance

The findings of this research revealed that emotional distance was a concept in which the perceived distance could be altered by participants, or at least, there existed a desire to change this distance. For some, this desire was to increase emotional distance from aspects of their caring identity. The data revealed sentiments of bitterness with the caring identity, a sensation of being *"trapped"*

within it (supporting the findings of Cormac and Tihanyi, 2006), and a strong desire to *"escape"* from it. This supports findings by Allen et al., (2012) who identified the importance of sharing the carer identity so that carers would not feel trapped, could take breaks from the caring identity which would prevent burnout of the carer. Reasons for the desire to increase emotional distance included carers being expected to put the needs of their care recipients above their own at all times (and doing so), supporting concerns raised by O'Shaughnessy et al., (2010) regarding tensions between meeting their own, and their care recipients' needs. This included needs such as health, whereby carers were never 'allowed' to be sick as there was no one else to pick up their caring duties. The carers felt they did not have time to visit their own GP or attend other health appointments because this often meant finding an alternative carer for the period, or bringing their cared for with them to their appointments which was not always practical. Cormac and Tihanyi, (2006) even suggest that carers suffer a reduced standard of health directly due to their caring role, either because of its demands, or because of the lack of focus on their own health needs. Carers felt that their own personal needs, such as social communication, physical affection, and even dietary requirements were overshadowed by those of their care recipient; made worse by the fact their caring role was 24 hours a day, seven days a week. The unceasing nature of the carer role meant that carers had no 'me-time' – no specific time off caring so that they could pursue their own endeavours, whether this was indulging in leisure activities (supporting finding by Chambers et al., 2001), or ensuring their own basic needs were met (for example, carers often bought ingredients and cooked a full meal for their care recipients, but prepared only a sandwich for themselves because they had ran out of time, ingredients, or simply couldn't be bothered. The findings of this research support those of Cormac and Tihanyi, (2006) who considered the mental and physical healthcare needs of carers and found that all too often, the needs of the carer were overshadowed by those of the care recipient, despite the fact that the health of the care recipient was also likely to suffer should the carer become ill also.

The findings also identified negative feelings such as frustration and imprisonment within their carer identity because they felt unappreciated. This appreciation was often sought from the care recipient themselves, but on

occasion recognition was also sought from wider society, in particular other family members, and also statutory services, such as social services. This was found to be a particular point of unrest with carers who felt they were providing a service to their care recipient, in replacement of a service which should be rightly provided by the local authority, hypothetically saving the Government money at the expense of the carer. This supports Arber and Ginn, (1990) who confirmed that informal carers saved the *"state a great deal of money"*, despite Dooghe, (1992) suggesting that it was the duty of informal carers to avoid input of formal care options for as long as possible.

The findings suggest that many carers are unhappy with their current identity and desire a transition to occur which would allow them greater emotional distance from the caring role which in turn would allow them greater opportunity to address their own needs.

5.3.1.3. Desire to decrease emotional distance

Conversely, findings also revealed circumstances whereby carers wished to decrease the emotional distance they occupied from the caring identity. Although this was not observed nearly as frequently as those carers wishing to increase emotional distance, the data revealed that on occasion, carers wished to transition ever closer to the carer identity. This was often a result of poor levels of existing care provision, or the worsening health or mental status of the cared-for. The data revealed that for some carers, the need to decrease emotional distance between the carer and the caring identity was not borne from a desire to do so, rather from feelings of guilt over the care recipient, either perceived by the carer alone, or through the manipulation of circumstance by the care recipient themselves. An example of this was shown in the findings section whereby the carer (daughter-in-law) had no desire to provide more care, increase frequency of contacts or transition her identity towards that of the carer identity. However, her Mother-in-law manipulated her goodwill, made her feel guilty for not cooking for her daily and pressed her status as vulnerable older person at every opportunity. The manifestations of carer identity transitions based on feelings of guilt are discussed later in this chapter.

Decreased emotional distance was generally achieved through increased frequency and quality of contacts, such as geographical relocation to be nearer

the care recipient, increased face-to-face contacts in replacement of remote contacts such as telephone calls etc. However, in a small number of participants, the desire to decrease emotional distance from the carer identity was not ultimately for the benefit of the care recipient, but was for the perception of virtuosity seen by others. The findings revealed a small proportion of carers who were motivated to provide increasing levels of care borne from the suggestion of a higher purpose; to achieve and out-meet expectations placed on them by family, friends and society as a whole. This opinion elevated their self-identity from mere carer to 'carer extraordinaire', selfless in thought and action and superior to other carers who did not embrace the carer identity so completely, and nothing to do with the quality of the relationship between carer and care recipient. The motivation to decrease emotional distance and to transition ever closer to the gold standard of carer identity (ultimately formed in the mind of these unusual carers) was linked to perceived competition with other carers (for example, one participant felt that a carer who did not give up work to provide care full time should not self-identify as a carer). The data suggested that these carers viewed their own selflessness in pious recognition of their own morality whereby only the truly selfless (i.e. those carers who have completely transitioned to carer identity with no aspects retained from their previous identity) can truly be seen in the carer identity by others around them.

5.3.1.4. Loneliness and Isolation

The Jo Cox Foundation, (2017) defined social isolation as a lack of social contacts and loneliness as a feeling of lack of companionship. Indeed both concepts were present in the findings of this research project. Loneliness and isolation have also been linked to poor physical and mental health and even increased mortality (Luanaigh and Lawlor, 2008; Steptoe et al., 2013; Victor et al., 2005). For Francine, social isolation was partly due to geographical rurality (mobile phone has no signal, roads out of the village can be closed in winter due to adverse weather conditions etc.) and the fact that she admitted she can go for days without speaking to anyone other than her husband, her care recipient. Francine also described feelings of loneliness with only her husband as companion but had acknowledged this and was keen to develop her social life to include others. To address this she became a member of the carers'

advisory group, and recommended socialising with neighbours. Francine also began to attend her spiritual and Church social clubs once again, having ceased regular attendance with the increased demands of her caring role. Francine felt her existence had become preoccupied with her carer identity and wished to change this. By manipulating the emotional distance between herself and other aspects of her life such as her husband, friends and neighbours she was able to begin the process of re-positioning her self-identity as something other than carer. In actuality, Francine was attempting to transition her self-identity back towards her self-identity prior to her caring role but acknowledged that any changes would occur by degrees, due to the complexities of the caring situation, which was uncontrollable and unpredictable (Schulz and Sherwood, 2008).

Many participants confirmed that they felt both socially isolated and lonely in their lives, primarily because of the effect of their caring role. Isolation and all-consuming focus on the carer identity (and ultimately the needs of the care recipient) was common in carers (Broady, 2017). For William, this manifested in feelings of being trapped in the caring identity - desiring change in identity but unable to manifest such changes due to his personal circumstances. Similarly Tim felt there was "*no escape*" from the carer identity, effectively echoing William in his desire to alter his self-identity away from carer but unable to do so. For Tracy, feelings of social isolation and loneliness were directly attributed to the change in identity she underwent, from successful career woman to carer. For these participants, the change in identity from their previous life, roles, responsibilities and relationships to their new life as carer with the associated life, roles, responsibilities and relationships was unwanted, uncontrolled and unwelcome. For these participants there existed emotional distance between themselves, their relationships with others and indeed their previous life. These participants missed the *"old-me"* and wished to reclaim aspects of it but were unable to do so through circumstance. In fact, for these participants in particular, the only way to bring about their desired changes in self-identity involved the death of their care recipient, supporting Broady's (2017) claim that the termination of the care recipient identity ultimately results in the termination of the carer identity. However, Broady, (2017) also acknowledged that the threat of death of the care recipient was particularly

traumatic for those carers who had completely transitioned their identity to that of carer through fear of the overnight loss of this identity. This was not seen however in the findings of this research.

Extensive research has been completed in the consideration of the care relationship, how it is formed, motivated, maintained and altered through the life course (Bengtson and Roberts, 1991; Cicirelli, 2000; Engster, 2005; Stuifbergen et al., 2008; White-Means and Hong, 2001). This research supports previous findings to surmise a number of motivating factors for the provision of care by family members.

The caring identity was accepted to differing degrees by participants of this study. Using Hughes, Locock and Ziebland, (2013) categorisation of carer identity absorption the participants' self-identity can be considered, as shown in the following table:

Table 3 - Carer Identity Absorption (adapted from Hughes et al.., 2013

Identity category	Participants
Embraced	Neil, Fred, Ian, Jayne
Enforced	Ashleigh, Emily, Ken, Bob, Katie
Absorbed	Edward, Karen, Jill, John, Francine, Margaret, Diane, Chris
Rejected	None

5.3.2. Moderators/Tools in identity transition

5.3.2.1. ECE Involvement

The data revealed that carers who wish to increase emotional distance between themselves and the carer identity often did so through increased utilisation of the wider ECE. Whether this was related to directly sharing aspects of the caring role with others, or just through increased communication with the wider ECE (and therefore communicating the hardships involved), carers felt greater emotional distance from the carer identity when they were not dealing with the

caring role alone. This was in part due to a fear of changing/new roles and responsibilities which they had not undertaken prior to the inception of the caring role. This included decision-making and taking control of financial management, being responsible for all household tasks etc.

The data revealed that carers may utilise the remainder of their ECE in an attempt to share the caring tasks associated with the caring identity, effectively limiting their own identity transition to certain aspects. For example, certain ECE members took responsibility for the household chores, another for financial management and another for direct care tasks such as washing and dressing. In this way, smaller identity transitions may occur for a greater number of ECE members.

The data revealed however, that within some ECEs the carer identity is fiercely guarded and not to be shared. For some participants, the primary carer (usually the eldest daughter, supporting research by Caputo, 2002) was not willing to share the carer identity with the remainder of the ECE. Only through the barring of further ECE member involvement could the carer transition their identity in the direction and to the extent that they wished, namely the self-identity of complete, sole carer. This supports Leinonen, (2011) who found that sibling carers for elderly parents often considered themselves the primary carer (each sibling within the same family reported that they alone were the primary caregiver) and that each sibling was unwilling to alter the proportionality of the care they provided – i.e. they did not wish to share or transition their identity of primary caregiver.

5.3.2.2. Objects, possessions and rituals in identity transition

The investment of artefacts and objects with emotional meaning is not a new phenomenon (Belk, 1988) and rituals and possessions can possess memories and links to previous times, reminding carers and their care recipients of previous shared identities (O'Shaughnessy et al., 2010). However the findings of this research showed this premise could be used in an attempt to inspire and instil emotional proximity to a place – that is, in the case of Jayne, her Mother's new home. Jayne used the same wallpaper in the house, the same objects and arranged them in the same layout as the previous house in the belief that her Mother's emotional attachment to her previous home could be transferred

through these objects. Jayne believed that possessions could act as conduits for exporting 'self' during a geographical relocation, as suggested by Noble and Walker, (1997). However Jayne admitted that this was not a successful strategy and that her Mother still took a long time to *"settle"* in the new accommodation. Epp and Price, (2010) state that possessions have transformative properties to assist an individual to integrate with change in a positive way, however also suggest that this can result in the possession losing its meaning and emotional value in a changed setting. They surmise *"furnishings and décor may contain memories and symbolize lineage"* Epp and Price, (2010 p.822). However objects' and possessions' emotional connections are *"context specific".* That is, despite a possession being gifted with emotional value, any contextual shift can result in the loss or modification of that value (Epp and Price, 2010). Jayne failed to consider the emotional bonds her Mother experienced to the social aspect of her geographic position – her community. Jayne confirmed that her Mother used to visit the local shops, was known at the local hairdressers etc. and had an emotional attachment to the area as the neighbourhood she had lived in as a married adult and where her children grew up in. This supports Gilleard and Higgs, (2005) who confirmed that the strength of these social bonds are important considerations for relocation plans and the rejection of the age in place choice for care of the elderly. Age in place (Gilleard and Higgs, 2005) however, was considered as the best course of action for Katie and John. Both admitted that John's Mother Ann had a deep emotional bond to the house she lived in and the area it was positioned. Ann was known in the local area, used local shops, utilised local community social groups etc. and both John and Katie agreed that the disruption the severing of these bonds would result in outweighed any benefits of moving her to more age-appropriate accommodation.

Loss of established rituals were found to have a profound effect on those involved and contributed to increasing emotional distance from the old identity. Although many of the findings found were related to loss or renegotiation of rituals for the care recipient, each example provided also had an effect on the ECE members, such as the addition of new responsibilities, or the development of, or participation in new rituals. The findings demonstrated that this was particularly apparent in rituals surrounding celebrations such as Christmas,

birthdays and other societal celebrations such as Halloween, because it is in the repeat of rituals that identity is constructed as the rituals become 'reality' for those involved (Cheal, 2002). The participation of individuals in these events were important factors in maintaining identity, the concept being "See! Nothing has really changed!", supporting Meske et al. (1994) who suggested that traditions and their associated rituals strengthen relationships, promote shared experiences and provide opportunities to build memories. For Dorothy in particular, her continued participation in Halloween celebrations was of great importance in maintaining emotional proximity to her former identity – she was no longer the old lady in the care home, but the wicked witch character she had played for numerous years before. This is explained by McKechnie and Tynan, (2008 p.1014) as a *"consumer identity project",* whereby consumers build identities using specific products at Halloween through dress up and role play which informs an individual's sense of self on a wider scale. Belk, (1990a) argues however, that Halloween allows the act of dressing up to confuse self-identity – that the celebration of Halloween allows participants to be someone other than who they are. In Dorothy's case however, this is taken a step further in that the ironic transition of identity to 'witch' allows her emotional proximity to her former life identity.

Although the data showed evidence of positivity in the loss or renegotiation of established rituals, this was not always the case. The findings revealed that the renegotiation of rituals involving Christmas were particularly difficult for participants. One ritual identified as being emotionally challenging was the purchase of Christmas gifts. Fischer and Arnold, (1990 p.333) suggest that this is because gifts given at Christmas are especially *"value expressive"* with an emphasis for givers to purchase gifts that reflect the emotional proximity of the gift giver and recipient; whereby the gift represents the "*givers valuation of the receiver"* (Fischer and Arnold, 1990 p.333). For Dorothy, the ritual involved in this consumption behaviour included saving up for gifts for family and friends, interrogating them for gift ideas, planning the shopping trip to purchase them with family members to take her, (when she would also pay for lunch out for the group), hiding the purchases until Christmas time and finally the wrapping and delivery of the gifts. The behaviour was highly emotive, and a way for her to demonstrate love, appreciation, emotional closeness and the successful

process of doing family (Barnhart et al., 2014). For Dorothy, her ill health meant she could no longer participate in this established ritual and instead bought gift vouchers for her family. The sadness that this change in ritual caused was significant, and affected her so much that she now did not look forward to the celebration of Christmas at all, and felt guilty that she had to ask her ECE members to purchase her vouchers for her, and the lack of imagination the actual gifts took. This concern regarding the reciprocity in the gift of vouchers supports Cheal, (1986) who suggests that there is an accepted expectation of reciprocity in Christmas gifts and therefore, concerns regarding the giving of vouchers was valid in this way. Mortelmans and Sinardet, (2004) also confirm that the gifting of money/vouchers does not express an interpersonal relation. This also supports the suggestion by Wong et al., (2012) whereby gifts given become (and remain) part of the extended self of the giver, offering an explanation as to why Dorothy continued to feel guilt and sadness regarding the purchase of vouchers.

This demonstrates that the loss of an established ritual can cause emotional distance from events previously used to confirm individual and family identities and secure emotional proximity. This supports Higgins and Hamilton, (2014) who suggested that experiential consumption (such as the process of purchasing Christmas gifts in this case) is a method for confirming family identity, to the family members themselves, but also to the outside world.

Data revealed the importance of renegotiating rituals for the purpose of sustaining aspects of previous identity for both the carer and cared-for. For Francine, the re-enactment of previous rituals with alteration were very important to her husband's self-identity. She recounted altering previous activities involving the vegetable garden maintenance by using indoor pots, compost and seedlings so that her husband could still take an active role. Whilst acknowledging that this activity wasn't quite the same experience, Francine was able to assist in the development of a new identity for her husband, based on previous life roles, despite this actually making more work for herself. The renegotiation of the gardening ritual for the cared-for, altered the self-identity of the carer, transitioning from having no contact with the garden, to now becoming the director or enabler of gardening tasks. Although this altered ritual

resulted in a shift in power between the carer and cared-for from previous positions in terms of gardening, the act itself resulted in positive experiences for both. This adds another dimension to the work of Phipps and Ozanne, (2017) who suggested that changes in power structures in routines can lead to insecurity and ultimately tensions amongst those involved.

The investment of meaning into objects was shown to be all the more important when used in conjunction with altered rituals. An old mixing bowl used as a conduit for baking and possessed for many years took on greater personal worth when used in a renegotiated ritual. The bowl had previously been used as a practical object, with utilitarian value whilst the care recipient was able to independently bake Christmas hampers for her family. Once she was unable to do so, the use of the bowl took on greater meaning, becoming a vessel for memory storage, a link with happier times and family Christmases past and a conduit for the sentimentality of feeding the family honest, home-cooked meals, as described by Trees and Dean, (2018) who connected home-cooking with a sense of sustenance, labour and love. This also supports Karanika and Hogg's (2013) notion that consumers' value in certain possessions increases over time as the object becomes *"layered with meaning via personal attention"* (Karanika and Hogg, 2013 p.911). The trajectory of this possession is of rising value to the self (Karanika and Hogg, 2013) and the replacement of the object cannot be considered because the emotional value it holds is irreplaceable which is of particular importance for possessions that reflect role within identity (such as wife, Mother etc.) (Karanika and Hogg, 2013). The baking ritual was re-negotiated due to the heaviness of the bowl and her daughter became part of the ritual, holding the bowl whist her Mother beat the mixture. At no point did it occur to the ECE to purchase a new, lighter bowl, or if it did, the idea was rejected due to the meaning attached to the old bowl, and the connotations to lost identity its disposal would bring about. In this way, the object became a link to previous identity and assisted in minimising emotional distance for all concerned. Likewise objects can retain their meaning and emotional value without being included in a new or altered ritual, and can maintain this value even if transferred to a new place, despite Epp and Price's (2010) suggestion that the meaning of objects may be circumstance-specific.

Dorothy had great emotional attachment to her motability scooters to such an extent that they became part of her extended self (Belk, 1988). Her self-identity included being the lady who went to the local shops daily on her big red scooter and Dorothy loved the fact that she was recognised by those around her. The link between her identity and the object was known and affirmed by the ECE members to such a degree that the ECE purchased her a personalised number plate which was affixed to the scooter. Dorothy's health deteriorated and she eventually went into residential care, however brought the number plate with her to her new home. Here she affixed the number-plate to her chair in her room, proudly showing it to visitors and recounting her tale of why the number plate meant so much to her. In this instance, Dorothy's emotional attachment to her possession was not lessened due to the change in setting. The possession kept its value as a link to happier times and positively affirmed the identity she occupied prior to her ill health. Although Lovatt, (2018) proposed that those who suggest objects help an individual to feel at home misunderstand the dynamic nature of identity and belonging, in this case, the fact that the number plate held static memories and attachments to identity was an important aspect for Dorothy and her ECE.

Epp and Price, (2010) consider new objects and altered rituals as possessing the ability to transform previous activities linked with identities into platforms for the development of a new identity based around the altered object and ritual. In effect, using altered rituals to form a new identity whilst maintaining semblance to the old. This can provide reassurance to both carer and cared-for alike, minimising emotional distance from previous identity in certain aspects of life.

The data exposed a further use of objects and renegotiated rituals as a tool to combat loneliness and isolation for both the carer and cared-for. Everyday objects such as a television and radio became links to wider society, methods for decreasing social distance between the user and the outside world and became a connection to other humans which was of particular importance at night. This concept is supported by Ongun et al., (2016) who confirmed in their research that media forms which do not require interaction remain more popular with the elderly and that radio listening helps to address feelings of isolation. For Chris, the renegotiation of an existing ritual became an integral way of both

providing care and increasing emotional proximity to his Father. Chris re-directed the previous ritual of daily telephone calls to his Mother towards his Father which served to decrease emotional distance between himself and his Father, despite the geographical distance between the two. The altered routine also assuaged Chris' feelings of guilt that he couldn't provide a greater range of caring duties for his Father and allowed a transition in his self-identity towards being a carer who performed his specified caring task daily, rather than just being a son. The altered ritual also served to minimise tension with the remainder of the ECE because they now felt Chris was contributing to the care provision for Robert – the remainder of the ECE did not have to transition their own self-identity to such a degree as a direct consequence of Chris' daily involvement. In fact, the renegotiation of this ritual also instigated the conception of another ritual whereby Chris and Robert would exchange postal letters, the content being emotive and heartfelt, sharing thoughts and feelings through the medium of the written word which they found difficult to communicate face to face. This new ritual also served to increase emotional proximity between the two.

5.3.3. Manifestations of the carer identity

Transitions to the carer identity can have a profound effect on the carers' wellbeing, according to researchers (Bevans and Sternberg, 2012; Carers UK, 2015; Parks and Novielli, 2000; Riche and Mackay, 2010; Schulz and Sherwood, 2008) and the finding of this thesis support this. The data identified many negative connotations of adopting the carer identity including suicide ideation, depression, loneliness, isolation and inability to cope. Aggar et al., (2011) surmise that this is because informal carers may struggle to find meaning in their new role and identity, however Shankar et al., (2009) suggest that this is ultimately because individuals feel discontent on the adoption of an identity ascribed by society and not the individual themselves.

Findings revealed that carers suffered changes to their behaviours and personality traits as a direct result of their identity transition to that of carer. They experienced emotional, social and psychological distance from their previous identity prior to the inception of caring which affected them personally.

This included increased propensity for anger / greater temper, increased general tension and feelings of hopelessness and even changes in physical appearance as lack of self-care often became an issue. These findings are supported by Carers UK, (2015) who also found high levels of depression, anxiety and stress in their carer poll. One of the main reasons for these manifestations was revealed in the findings of this researcher as anger and resentment at their perceived lack of choice when it came to identity transition. Findings suggest that carers felt that their identity had transitioned to that of a carer without their acceptance, or even understanding of what that transition would be like in reality. This supports Aggar et al., (2011) who identified that anger and resentment in informal carers has a substantial impact on the carer experience. Permission for the carer's life to change was not sought, nor given; rather any number of circumstance forced the transition of their identity. This manifested as feelings of 'distance' from their previous identity, and more importantly, a way to transition back (even in a small way) could not be seen. Aggar et al., (2011) also found that resentment of the carer identity was higher in individuals who had to give up paid employment and/or leisure time, a point supported by this research.

This research has demonstrated that carers who are unhappy with their identity struggle to find any tools or assistance to make the transition in reverse – from their carer identity back to their identity prior to their caring role. This ultimately may only occur on the death of their care recipient, when both the carer and cared-for identity cease to exist, supporting O'Connor, (2007) in that one caring identity cannot exist without the other. *"Anticipatory grief"* (Baikie, 2002 p.291) suggests that for the spousal carer, the death of the care recipient with dementia occurs well before the individual takes his or her last breath, and can be epitomised by Almberg et al., (2000) cited in Baikie, (2002 p.291): *"neither a wife nor a widow".* The findings also support Daly et al., (2013 p.504) regarding the reality of carers *"living on the fringes"* and Broady, (2017) regarding the importance of alternative role identifications as part of the carer identity in an effort to prepare for its eventual termination. The findings of this research however, did demonstrate the importance of peer support groups, such as the Carers Advisory Group of which the majority of participants were a member. This supports O'Shaughnessy et al., (2010) who confirmed in their research that

regular contact with other spousal carers provides emotional validation, support, acceptance and understanding.

5.3.3.1. Changes in roles and responsibilities

Although potentially a change in the carer themselves, findings showed that the carers' inability to *"switch off"* from the caring role had profound effects on their wellbeing. The carer role has *"no finish time"* and so carers felt unable to *"switch off"* or *"wind down"*, particularly when co-residing with their care recipient. This conspires to provide the carer with no emotional or psychological distance from the carer identity and adds to the state of high frustration, stress and burden as a direct result of caring. Arber and Ginn, (1990) also found that the number of hours spent caring was higher among carer-cared for co-residences and that this increased with the age of the care recipient, supported by the findings of this research.

The findings demonstrated that the transition to the carer identity brought with it changes in functional roles and responsibilities, such as taking the lead, or becoming solely responsible for household management, including cooking, cleaning, repairs, laundry and financial management and bill paying. Carers felt overwhelmed on occasion by the diversity of their new identity, for which they had received no training, but had to learn on the job. Carers UK, (2018) support the claim that carers feel unsupported and lack information. They call for the Government to ensure that carers are prepared, supported and informed in their caring role to ensure their own health and wellbeing. The data revealed that carers struggled to manage new roles and responsibilities as a reflection of their change in identity and that this was exacerbated in some carers by the loss of their paid employment. Baikie, (2002) suggests that this is because, in successful relationships there must be a balance of contributions to the relationship and the benefits they get from it, which is lacking in spousal informal care relationships and results in distress on the part of either (or both) carer and cared for when the disproportionality is recognised.

Paid employment often forms part of self-identity and its loss can have a great effect on carers as they may struggle to re-identify themselves as a carer. This was the case for a small number of participants who felt that they had lost the prize that they had been working towards all of their working lives. The findings

also suggested that carers may struggle to marry their previous employment identity with their new carer identity because they are so different, requiring different skill sets. These findings support those by Barnes et al., (1995) who suggested that carers may become increasingly depressed, isolated and resentful of their caring role if they feel they have sacrificed themselves professionally.

The data demonstrated however, that in some cases, changes in roles and responsibilities were welcomed by the carer as they altered structures of power and agency in their relationships. For Catherine and Francine in particular, the inception of the carer-cared for identities gave them control of the finances of the household for the first time in their lives. This agency allowed them to make decisions over aspects of their life which had not been within their identity prior to this. Although both admitted to feelings of nervousness and fear about the enormity of their new role, both relished their new-found ability to call the shots, supporting Moore, (2016) who surmised that the possession of agency is a personal construct which ultimately contributes to one's sense of self.

For the purposes of this research, roles, responsibilities and identities are seen as separate constructs, although do overlap. This supports Kleine et al., (1993) who confirmed that identity and roles are different constructs. It is possible to view the following section by considering the change in roles and responsibilities exclusively. However, the author feels that this would be detrimental to the consideration of the importance of identity. Arguably, individuals possess many different identities – not just roles and responsibilities within one overarching identity (Ahuvia, 2005; Al-Abdin et al., 2016; Belk, 2014). This is because different roles and responsibilities require different aspects of the person – different strengths, different emotional attachments and even different social and moral codes. An example of this is one participant who cared for his Father. This caring identity required his patience, his emotional strength, his diplomacy and balanced reasoning, his abilities to multitask and learn new roles quickly and his ability to display affection and love. This role required personal communication skills on a one to one basis. The same participant was also in paid employment – a role arguably requiring the ability to apply knowledge practically, to work independently and professionally and to be

able to lead others. Communication skills were of a professional basis, using professional language and addressed to an audience of similar experiences and skill set. The same participant was also involved with his local amateur football team. This role required strength of character, emotional invisibility, physical strength, teamwork and also the morally dubious ability to cheat for the good of the team. Communication was loud, explicit and used language only expressed on the football field (swearing etc.) This example demonstrates how different roles and responsibilities can lead to the existence of multiple identities that carers may have to manage. This supports findings by Stephens and Franks, (1999) who recognised that competing roles, responsibilities and ultimately identities can have a significant impact on the wellbeing of carers and responds in part, to their call for further research into further understanding carers with multiple roles. Their competing demands and expansion hypotheses (both found to be partly valid in their own research) were not tested by this research, but findings in this research concur with Stephens and Franks, (1999) in that the picture of multiple roles is extremely complex. This research also supports Kleine et al.'s (1993) view that different identities carry different levels of emotional value and that possessions and artefacts associated with different identities also differ in emotional value and over time. The findings of this research also support Dwyer et al., (1994) in their conclusion that the competing demands of multiple family responsibilities result in stress and burden to the carer.

Findings indicated that struggles in acceptance of the carer identity were exacerbated by the multiple roles carers were expected to undertake, effectively inhabiting a number of different identities at the same time. For many, the carer identity was just one of a number of identities the carer was expected to carry, from Father, Husband, Son, Friend, Brother, work colleague etc. In fact, one participant described himself as a tree, possessing a number of branches that many people needed to take from him. In effect, balancing his different identities caused a great deal of stress and frustration and caused fear regarding the addition of any further identities which may result in the loss of others (for example, giving up work to provide full time care). The multiple identity struggle was exhibited to a greater extent in filial carers in this research, but not more in female carers, which did not support the findings of Stephens and Franks,

(1999). The findings regarding the complexities of multiple identities also support Leinonen, (2011) in part, with specific emphasis on the balance of the carer identity with employment identity. The findings highlighted the possibility that the uptake of the carer identity may be limited in response to employment status and hours worked, and as a consequence, may be more likely to be shared with other siblings.

5.3.3.2. Changes in relationships

The findings established increased tension between ECE members with changing identities, responsibilities and roles associated with the inception of the caring identity. This was particularly apparent in ECEs that resided together – carer, cared-for and other members of the family (although this type of ECE arrangement was rare in the findings). The living arrangement exhibited similar tensions as those seen in carers with multiple identity constructs. The primary carer struggled to maintain the various identities, all requiring different aspects of character and temperament whilst residing under the same roof. Neil, who brought his elderly and infirm Mother to reside with himself and his wife felt a responsibility to provide care full time, but also to shield his wife from the physical and behavioural issues his Mother displayed. This resulted in his wife physically relocating herself away from the source of tension when the situation was at its worst, by leaving the house in the evenings, creating emotional distance between herself and her husband. Neil became dejected from his failed and constant attempts to balance his competing identities and felt guilt towards his wife that he had caused their emotional distance by moving in his Mother.

A further theme of tension among ECE members with the addition of the caring identity was frustration with other members failing to pull their weight – essentially failure to share the caring identity. Most ECEs were found to conform to a primary caregiver and back up care model (Leinonen, 2011) whereby one carer would lead care provision and decision-making and attempt to impose their ideas or instructions on the remainder of the ECE. The proportioning of the carer identity was complicated further by geographical distance between ECE members. Tensions occurred in ECEs if one member felt the proportionality was incorrect or unfair – that one member had adopted

the carer too much and others not enough. This was seen to occur in both carer identity transition directions, whereby one carer may wish to re-assign aspects of the carer identity to transition back towards their previous identity, but also in carers wishing to absorb further aspects of the carer identity by taking aspects of it away from other ECE members. The findings demonstrated that these transitions were controlled by the realignment and re-assignment of caring tasks between ECE members, supporting Checkovich and Stern, (2002) claim that the majority of care is provided (or at least orchestrated) by a single caregiver, but also supports Tolkacheva et al., (2014) that there are often multiple siblings involved in the provision of care, when all aspects of the role are considered.

The research identified a number of tensions in emotional distance experienced by the care recipient, resulting in pressures on the carer – cared for relationship. An example of this was the fear of interference of the carer and/or wider ECE in the every-day life of the care recipient – essentially the desire to increase emotional distance from the perspective of the care recipient. This may have significant consequences for the carer, as they may feel their carer identity is being rejected. This desire to increase emotional distance by the care recipient was seen in the findings in two distinct ways. Firstly, the care recipient was seen to overtly defy the orders of the carer. An example of this was seen in one participant whereby the care recipient was described as flouting the carer's instructions to remain downstairs and not venture upstairs in the care recipients own home, due to the carer's fear of her falling down the stairs. The care recipient continued to use her upper floor but denied doing so when questioned by the carer. The carer became increasingly frustrated when her attempts to physically bar access to the second floor were thwarted (baby gates on the stairs, removal of bedding from the beds and the eventual installation of physical block on the stairs). The perceived disobedience of the cared-for by the carer resulted in increased tensions between the two and the threat of withdrawal of the carer identity as a method for manipulating the behaviour of the care recipient (the carer stated to the care recipient that her visits would cease unless she stopped using the upper floor and putting herself at risk). Her subsequent compliance with her carers request may have secured her further care and the continuation of the carer identity for the carer, but possibly

increased the emotional distance between the two, detrimentally affecting the quality of the care relationship.

Secondly, the care recipient was seen to covertly defy the orders of the carer in this research. One participant was emotionally close to his ECE, but felt that their demands became *"bossy"* and overbearing at times. In this particular instance, the ECE wished their elderly parents to purchase new chairs that allowed them to stand and sit with greater ease. The elderly parents had no desire to do so, being happy with the comfort and performance of their existing chairs. However, they allowed the ECE to purchase new chairs (using the elderly parents own money) in a tacit expression of compliance (supporting wider literature on the group phenomenon of consumption by care recipients including Barnhart et al., 2014; Barnhart and Penaloza, 2013; Epp and Price, 2008; Lee and Collins, 2000). The elderly parents then stored the new chairs in another room and continued to use their existing chairs, until such a time when a visit by the ECE was expected, at which point the new chairs would be brought out with the pretence that they were in constant use. As soon as the visit was over, the chairs would be swapped once more and stored for the next visit. This covert deception allowed minimal emotional distance to result from the differing points of view. The ECE did not feel frustration at the non-compliance of their parents, but the elderly parents did not feel overly pressured into using objects they did not wish to. Caring identities were unaffected by the battle of wills because the battle was never freely admitted to. The preservation of emotional proximity within the ECE allowed the elderly parents to embrace their identities as care recipients without fear of reprisal from their covert acts of defiance. However, both examples used support Clements, (2013) to some extent in that persons disabled through age, infirmity or physical disability are largely viewed by others (including their carers) as non-verbal and compliant in going along with the wishes of others, and if they are not, some carers believe they perhaps should be!

As previously discussed, the findings revealed that feelings of guilt can be used as a motivator for carer identity transition. In an example used previously, a participant was made to feel guilty for not desiring a transition of her identity towards that of full carer, by the care recipient. The care recipient's attempts to

manipulate the carer's feelings to essentially decrease emotional distance actually resulted in the opposite. The carer became frustrated with the care recipients attempts to manipulate her, and became angry that her existing efforts were not appreciated. This tension served to increase emotional distance between the two and actually the frequency of contacts provided by the carer reduced because of it. The use of guilt as a tool to transition identity in this case worked in reverse and the carer identity transitioned towards that previously occupied.

Conversely, the data revealed increased emotional closeness in an ECE in which the care recipient laid no expectation of care provision (essentially no guilt) at the feet of her family. Geographically spread, the ECE provided no direct care to the care recipient, but did provide ancillary care tasks such as financial management and general arms-length household assistance (such as organising tradespeople etc.) The lack of expectation by the care recipient for the ECE members to transition their identities towards that of carer served to maintain emotional proximity within the group and actually led to certain limited identity transitions towards that of the carer identity to occur (such as one member of the ECE deciding to visit more often to manage her Mothers redecorating project and to organise the provision of formal care to greater effect.)

5.3.3.3. Change in relationship labels

The data revealed that changes in relationship labels (from familial role such as husband or daughter etc. to carer) and the associated change in self-identity of the carer was more problematic for carers that co-reside with their care recipient and in spousal carers. For Carol, Susan and Yvonne, the very fabric of their relationships with their husbands changed on becoming their carer. These participants referred to themselves as "*carer*" and their care recipient's as "*another child*", "*stranger*" and "*dependant*", instead of their former identity of wife, lover and friend. The strength of the feelings of loss in this change in identity was shown to have a profound effect on the mental health of the carers involved. Their frustrations and sense of grief at the loss of the relationship label and the transition in self-identity brought about by it was formidable. The addition of their caring role had brought about changes in their self-identity

whereby their previous labels, roles and responsibilities had been replaced with that of carer and this change was neither expected nor desired. Of particular poignancy was the loss of relationship aspects that had previously made the marriage successful, such as communication, friendship, shared interests and a physical/sexual relationship, supporting findings by O'Shaughnessy et al., (2010). The data revealed that carers believed the complete identity transition from wife or husband to that of carer was confirmed by the loss of these aspects and that the loss of the previous relationship status was the hardest aspect to contend with on an emotional level, not just because of the grief for the lost relationship, but also for the knowledge that in most circumstances, this loss would be irreversible, supporting Dempsey and Baago's (1998) theory on latent grief in some carers. The findings in this research do not support O'Shaughnessy et al., (2010) who suggested that previous relationship identities of the carer and cared-for and the strength of their relationship prior to illness can affect how the changes in the nature of their relationships affect identity as that illness progresses. They suggest that strong relationships between spouses make it easier to *"preserve the personhood of their partners"* which then allows them to *"preserve their own identities as husbands and wives"* (O'Shaughnessy et al., 2010 p.239) and their findings are supported by Baikie, (2002) who also suggested that the quality of the relationship prior to caring impacts the level of caregiver burden and stress suffered in later times. Data from this research however, did not show this to be the case – regardless of the strength of the relationship before the illness (or caring commenced), carers struggled to accept the changes in their relationships and the loss of their previous relationship identities, although the object of this research was not to measure either strength of relationship or level of carer burden or stress.

This research has identified the transient nature of the carer identity, transitions which can be motivated and moderated by discontent with emotional distance. This chapter has demonstrated a number of aspects which motivate a desire to change self-identity and a number of methods for bringing about the desired transition, whether through the use of possessions and artefacts, the realignment of rituals or through adjustments in the constituency of the ECE itself. The chapter has also revealed what manifestations to the carer identity can be once transitions have taken place.

The following section identifies the above in a conceptual model which highlights the cyclical nature of changes within the carer identity and the changes in identity which may occur by degrees during this liminal phase of identity transition, until an optimal identity has been reached and aggregated (Noble and Walker, 1997).

5.4. Conceptual Framework

The conceptual framework below demonstrates the existence of an optimum position for carers self-identity (SI) based on a continuum between their previous life identity - activities, roles, responsibilities and relationships (PLI) and their caring life identity - activities, roles, responsibilities and relationships (CLI). For each individual, their position on this continuum will be dictated by their own personal circumstances, desires and characteristics; likewise their desired direction of travel (if indeed movement is desired – i.e. the participant is unhappy with their current self-identity) will also be specific to each individual.
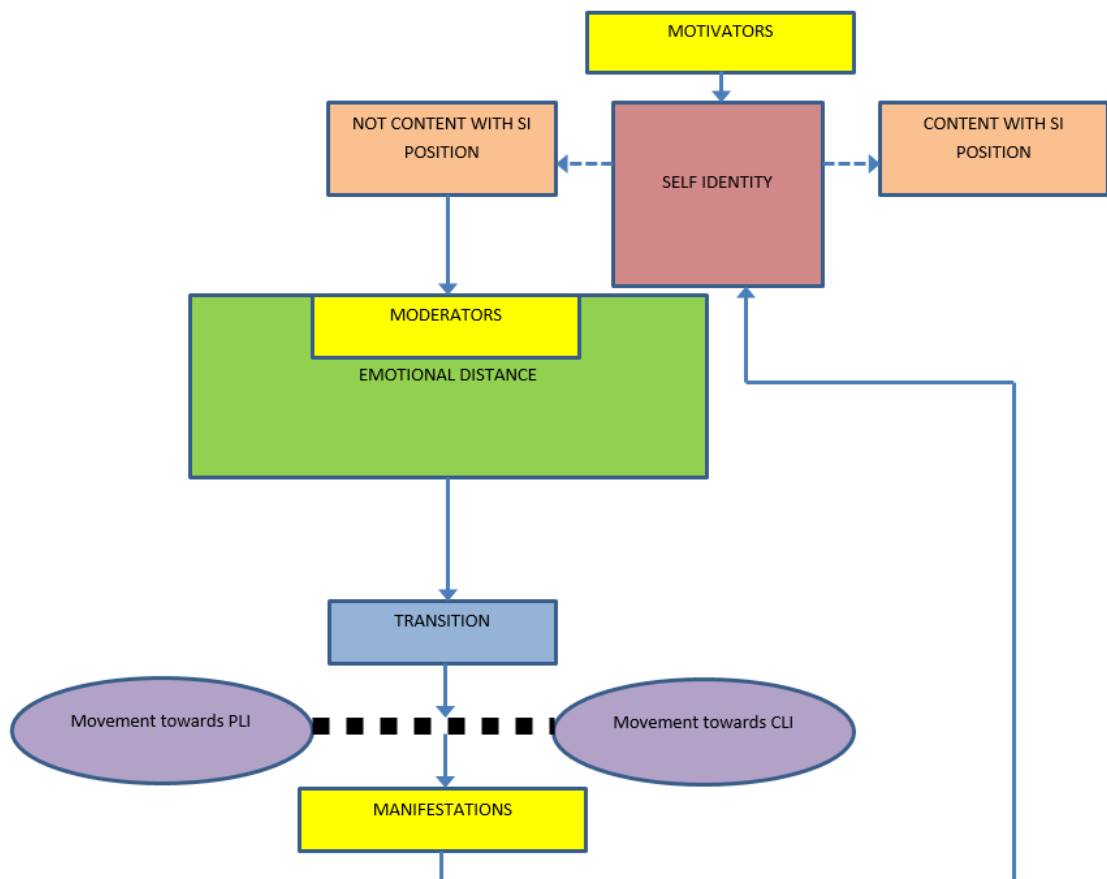

Figure 1 - Conceptual Framework of Identity Transition Process

5.4.1. Conceptual framework description

- Self-identity is positioned on a continuum between PLI and CLI according to individual characteristics, circumstances, experiences etc. An individual may be satisfied with their self-identity or may desire changes within it.

- Discontent with existing self-identity is examined by the individual themselves and *motivators* identified by the individual to identify and explain the source of discontent.

- Emotional distance is the vehicle to bring about the desired change and can be used in a variety of ways to alter self-identity and positioning on the PLI/CLI continuum.

- Tools to assist a change in self-identity known as *moderators* are used to alter the relative degree of emotional distance in specific aspects of self-identity. These moderators are set within emotional distance as they work from within to alter the emotional distance experienced by the carer in that given situation. There may be one or several moderators acting within emotional distance at any given time. Moderators can increase or decrease emotional distance and include the commencement, alteration or ceasing of rituals, use of possessions or artefacts, but also other intangible aspects such as ECE member involvement and role changes, situational changes etc.

- The use of moderators produces a transition, that is, a change in direction and/or movement by degrees on the continuum between PLI and CLI.

- The process of transitioning has re-positioned the individual's self-identity on the PLI/CLI continuum which has effects on one or more aspects on that individual's identity. These are *manifestations* or results due to the transition and re-positioning of the individual's self-identity.

- The new self-identity is accepted by the individual who is either content or not content with this identity and its relative position on the PLI/CLI continuum. If content, self-identity remains static. However if the individual is still not content or if further motivators are identified, the process for the re-definition of self-identity and re-positioning on the

PLI/CLI continuum begins again until individual, optimal self-identity and positioning on the continuum is reached.

5.4.2. Worked example

Edward sees his Father Robert once a week on Sundays and provides basic care assistance such as taking him shopping, checking his welfare and interacting socially with him by taking him out to lunch. Edward is content with his caring self-identity which is positioned to the far left of the PLI/CLI continuum.
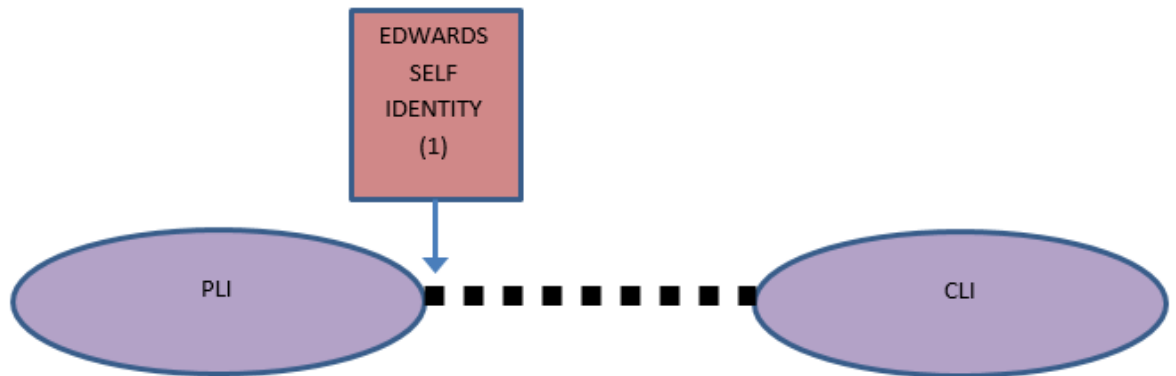

Figure 2 - Edward's Original Position of Self-Identity

Robert is involved in a car accident and can no longer feed, dress, wash or care for himself due to his injuries. He is also emotionally and mentally unstable due to the effects of his own injuries, but also the tragic loss of his wife in the car accident.

Edward recognises that Robert now requires more care and needs constant help –physically, mentally and emotionally, and so Edward decides to move in with Robert, also taking his wife Karen and their two children to assist in the provision of care.

This change in self-identity and position on the PLI/CLI continuum can be seen in the table on the following page.

Table 4 - Edward's Self-Identity Transition - Motivators, Moderators and Manifestations

Motivators	The love and affection Edward feels for his Father
	The duty and obligation he feels to care for his Father who is now alone following the death of his wife, and also the responsibility Edward feels as Roberts eldest son
Moderators	Ritual changes – instead of seeing Robert once a week and taking him out shopping, Edward will now reside with him and take the lead in providing all caring tasks for him
	ECE Involvement changes – Karen has also agreed to move in with Robert and she is prepared to help with taking care of Robert, in particular to assist in the personal caring tasks such as washing and dressing Robert
Manifestations	ECE structure changes – Instead of Edward visiting his Father alone on Sundays, Edward and Karen are both actively involved directly in caring for Robert
	Changes to roles and responsibilities – Instead of general checks on his welfare, Edward is now responsible for Roberts entire welfare, including basic life needs such as food provision on a daily basis

These manifestations have repositioned Edward to the far right of the PLI/CLI continuum. His new identity is centred on being a carer for Robert. Edward has taken leave from his employment so he can be with his Father 24 hours each day and changed his living arrangements to provide the level of care required. Edward recognised the enormity of the roles and responsibilities involved in caring for Robert and so asked his wife Karen to move in too to help in the more personal caring tasks such as washing Robert.
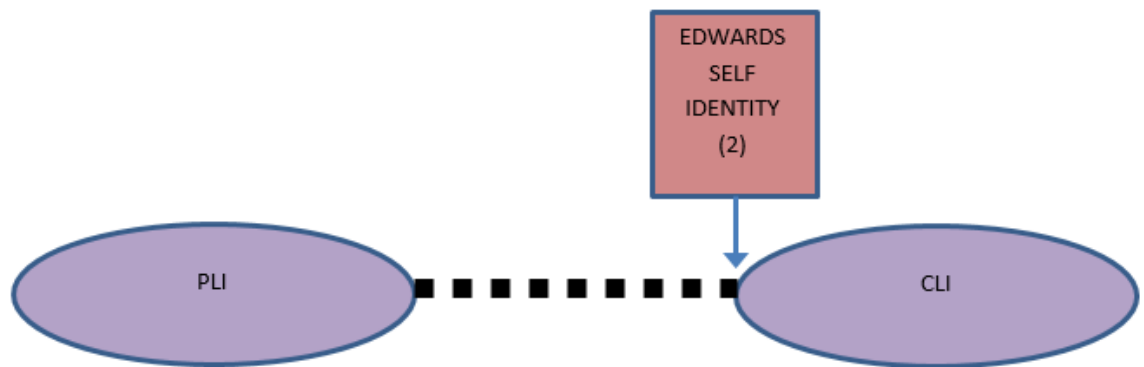
Figure 3 - Edward's Second Position of Self-Identity

Edward is not content with his new carer identity. He is not used to living with his Father, misses his job and tensions are emerging between Robert and Karen who are beginning to argue. Robert's health is returning but he remains very depressed, still grieving the loss of his wife. Edward is also recognising tensions between himself and Karen who has maintained her employment but now her drive to work takes 30 minutes each morning rather than the usual 10 minutes. Karen is also getting angry when Edward takes Robert's side when they argue which is increasingly occurring. Managing the children's after-school commitments are also becoming problematic and the children are unhappy living at Grandad's because they miss playing with their friends and their games consoles and toys at their own house. The children also complain that Grandad is very short-tempered with them and are beginning to cry at night that they want to sleep in their own bed.

Robert is now able to wash and dress himself but still requires assistance with shopping, food preparation and cleaning. His mental state remains a worry. Edward's brother Chris lives over 200 miles away but agrees to be more active in caring for his Father and agrees to telephone him every day to check on his welfare. To allow this, Edward buys Robert a mobile phone to keep on his person at all times. Edward realises that he needs to change his self-identity and re-position himself on the PLI-CLI continuum and decides to move his family back home and to visit Robert every other day after work. Karen has promised to take Robert shopping at weekends to buy food to include

microwave meals and agrees to cook an evening meal for him which Edward can then take on the days he visits.

Table 5 - Edward's Re-Transition of Self-Identity - Motivators, Moderators and Manifestations

Motivators	Love and affection for ECE members – Edward realises his new carer identity has caused tensions between himself and Karen
	Loneliness and Isolation – Edward feels isolated in caring for his Father, he takes care of him 24 hours each day, never leaves the house other than for caring tasks such as shopping
	Social needs – Edward feels that he needs to socialise with friends and do other activities that don't involve his caring role
	Health needs – Roberts health has vastly improved and he can provide his own basic care
Moderators	ECE involvement changes – Chris has promised to ring Robert every day to check his welfare
	Rituals – Edward will visit his Father every other day, straight from work, instead of living together. Karen has promised to cook for Robert as much as she can and Edward will take plates to his Fathers when he goes to visit
	Possessions – Edward has bought Robert a mobile telephone so that the family can check on his welfare easily
	Artefacts - Karen will purchase frozen ready meals for Robert to ensure he has access to a meal without having to cook from scratch
Manifestations	Changes to roles and responsibilities – Edward will no longer have to provide all caring tasks for Robert
	Changes to ECE structure – Chris will now be involved in caring for Robert and Karen will not have to provide all direct care for Robert

These manifestations have re-positioned Edward from the far right of the PLI/CLI continuum towards the left of the continuum. Edward's position remains further right than it was originally as he has far more carer involvement with his Father than he used to, but far less than he did whilst living with him. Edward is

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now happy with his self-identity, the position of this identity on the PLI/CLI continuum and the emotional distance between himself and Robert.
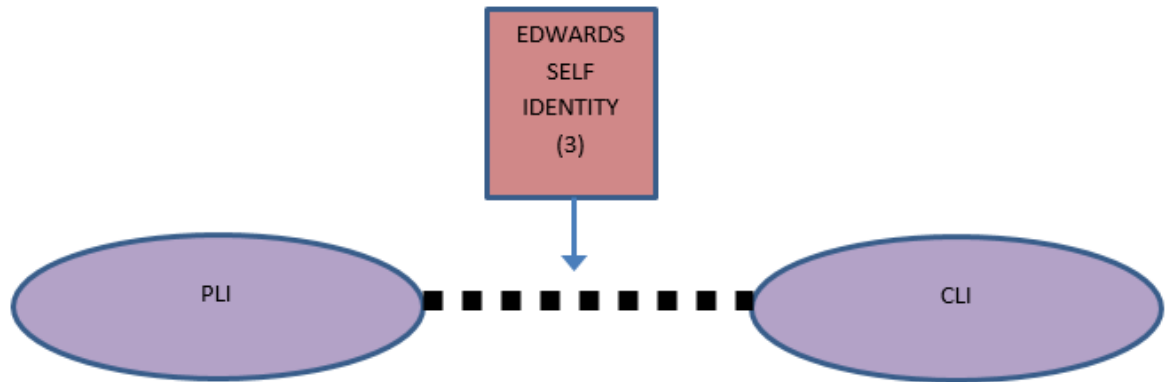

Figure 4 - Edward's Third Position of Self-Identity

5.4.3. The transient nature of the carer identity

The above conceptual model has demonstrated the transient nature of the carer identity, where movement in identity relies on the manipulation of emotional distance. The framework utilises 'motivators', 'moderators' and 'manifestations' to demonstrate the aspects related to that change and demonstrates a clear argument for the transient nature of the caring role. The main points identified by this research are as follows:

- The addition of the caring role results in self-identity changes from PLI towards CLI.

- Each individual has an optimum position on the continuum based on their individual characteristics and circumstances

- Emotional distance is a concept that can be used to transition individuals along the continuum in both directions

- A desire for change in identity course can be stimulated by a range of factors such as love or obligation etc. These then become *Motivators*

- Emotional distance can be manipulated using a range of *Moderators* that act within emotional distance, such as objects or rituals

- The result is movement along the continuum in the direction dictated by the individual's circumstances and produces changes in the individual's

self-identity such as changes in role and responsibility, relationship changes etc. These factors are characterised as *Manifestations.*

Chapter 6. Validity and Limitations

6.1   Validity/reliability

6.2   Generalisability

6.3   Limitations

6.1. Validity / Reliability

Reliability in a qualitative study, according to Golafshani, (2003 p.601*) "has the purpose of generating understanding",* and is based somewhat in the trustworthiness of the researcher themselves (Golafshani, 2003). A phenomenological approach has been taken throughout the planning, execution and write up of this research study in an effort to understand the experiences of its participants. The reliability and validity of this study is discussed below with emphasis on the phenomenological nature of this research.

Validity, or quality control (Kvale, 1996) seeks to confirm the truth of the knowledge gained from the specific research study (Kvale, 1996). Qualitative interviews can seek to approach objectivity through their intersubjective standpoint (Kvale, 1996). The validity of this qualitative study was not based on the objectivity of the findings - a critique by some scholars, highlighted by Kvale, (1996) being that researchers using interviews as a basis for theory production are picking one interpretation out of many potential interpretations; that objectivity is lost in qualitative research involving interviews. However Kvale, (1996) proposed that this suggests that there is only one true interpretation to be uncovered whereas in fact, "*multiple perspectival interpretations is a specific strength of interview research" (Kvale, 1996 p.212).* Abma et al., (2012) agree that validity/credibility and rigour in qualitative research means that:

> Researchers acknowledge their role as interpreters, they do not reveal a pre-existing truth, but actively construct and ascribe meaning to interview data – to stay as close to the meaning of the respondent as possible.
>
> Abma et al., (2012 p.30).

Tracy, (2010) recommended the use of eight criteria for quality qualitative research which are to: encompass a worthy topic, apply rich rigor, conduct

research with sincerity, conduct research with credibility, identify the resonance of the work, identify the significance of the contribution, highlight ethical considerations and then confirm the meaningful coherence of the research. These criteria are supported by Kvale, (1996) who suggests similar principles in confirming excellence in qualitative research. Kvale, (1996) uses three communities of validation to ensure research based on interviews is credible. Firstly, validation with the interviewee, whereby the researcher must keep his or her interpretations within the contexts of those meant by the interviewee. This was conducted in this research and supported by the process of re-interview (which occurred in this research project as far as possible) which helped verify interpretations made by the interviewer, with the interviewee. Secondly, validation with the general public, whereby the interpretations drawn are made bearing in mind the understanding of the general public – that validity can be evidence by *"whether a consensus may be obtained that an interpretation is reasonably documented and logically coherent"* (Kvale, 1996 p.217). This was attempted in this research project through involvement of specific PhD community support forums (taking into account the necessities of confidentiality and other statutory regulations). Thirdly, validation with the theoretical community, whereby the theoretical cogency of the interpretations made are valid for the subject area studied, and that those interpretations follow logically from the theory – a presupposition that the validity of theoretical interpretation is based on *"specific theoretical competence"* (Kvale, 1996 p.218) For the purposes of this research, this has been conducted through the supervision process that PhD candidates undergo with a senior researcher at the University.

Kvale, (1996) argues that validity or reliability of research is not a process or checklist to be completed at the end of the project; rather it is a continuing process which should be addressed at each stage of the research. In response to this, Kvale's (1996 p.237) *"Validation at seven stages"* has been used throughout the production of this thesis to ensure theories developed are sound, well-grounded, justifiable, strong and convincing (Kvale, 1996).

The first stage of this process is "*Thematising*". The logic and presuppositions of this study have been thoroughly researched and demonstrated throughout, from a comprehensive literature review to identify what is already known, to the

formulated research questions to explicitly identify what this research is addressing.

The second stage is "*Designing*". The knowledge produced in this study was based on the premise of study design and methods which directly reflect the research questions – that is to understand the phenomena of carer identity transitions through the lived experienced of the participants. This was fully investigated and recorded in the methodology chapter of this thesis. The ethical considerations of those involved in the study were identified and deliberated carefully, (as seen in the method chapter of this thesis) and the benefit to the human situation of the research weighed against the risk of harm to the participants.

The third stage of validity is "*Interviewing*". The quality of the interviews and subsequent treatment of the data has been explicitly recorded in the methods chapter of the thesis, demonstrating validity in the interview process.

The fourth stage is "*Transcribing*". The validity in the transcription process has been explained in the method chapter, and was conducted solely by the researcher and included all data sources such as field notes etc.

Stage five of validity is "*Analysing*". An abductive approach to analysis was adopted as theory construction was the overriding aim of this research. Detailed descriptions of the analysis process were included in the method chapter of this thesis. The analysis of the data was therefore *"logical"* and *"sound"*.

The sixth stage relates to issues of "*Validating*". As demonstrated in the method and methodology chapter, Kvale's (1996 p.189) *"Six steps of analysis"* was used to evidence the validity of the research process which was reflected on throughout the research completion and in particular, the analysis of the data from which meaning and theory were constructed.

The seventh and final stage of Kvale's (1996 p.237) validation stages is "*Reporting*". This refers to deliberation and confirmation that the overall report of the research gives a cogent account of the findings, confirmed by the author.

The benefits of a phenomenological approach to this research are that the reader understands the experience of the subjects better (Creswell, 1998). The aim of the researcher was to produce a research report that provides a clear

and accurate description of the phenomenon (in this case, the concepts of distance in informal carers and the effects this has on identity transitions) experienced by its participants only. Although a conceptual framework has been produced, this theory generating is reflective of this study only, although may well resonate with others in a similar situation. Because of the research design, bias has not been explicitly considered as it is inherent in the social interaction of the interview. To attempt to eliminate bias would be senseless as the data gathered cannot be separated from the social interaction from where it was produced (Mason, 2002).

6.2. Generalisability

Kvale, (1996) suggests that qualitative research relies on naturalistic generalisation whereby personal experiences and understandings form the basis of how things are (Kvale, 1996) and leads qualitative researchers to develop expectations instead of explicit predictions regarding how others may act in similar situations. Thus, rather than questions regarding the generalisability of a research study such as this, the questions become about the resonance of the study – does it resonate with others in a similar situation? (Cunliffe, 2017) - the objective becomes *"knowing"* rather than *"knowledge"* (Cunliffe, 2017). Abma et al., (2012) agree that generalisation is not a necessary contemplation for qualitative research and states: *"Results can be discussed in terms of transferability instead of generalisation"* Abma et al., (2012 p.31).

The findings of this research and the theoretical contributions made from it can be transferred to many other situations in which the experiences of informal carers are examined. The need to understand the transition of carer identities will resonate with others in similar situations in research where parallels may be drawn between different research groups.

6.3. Limitations

This section identifies the limitations of this research, from research methods, the findings of the study and also the theories developed from it.

The study consisted in total of 19 face to face interviews and 12 anonymous statements. The anonymous statements were submitted in response to a call in a local authority magazine requesting carers get in touch to share their experiences of being a carer. This suggests that the participants that provided statements, firstly took an interest in local community (to read the magazine in the first place) and that these participants wished to share their experiences with others (including the local authority) which may suggest that they had particularly negative experiences, desired specific actions from the local authority and/or wider society and were unconcerned at sharing the personal nature of their caring experiences. This may suggest that these participants

were not truly representative of the wider population. However, any participant of research similar in nature to this study has confirmed their willingness to share their experience by definition of being an informed participant who has provided informed consent. Often, this is for the very reason that their experience has been exceptional in some way, with the belief that society as a whole would benefit from being informed of it. The approach to this research was qualitative in nature and described the experiences of the participants only and therefore, does not attempt to generalise the findings– although as previously discussed, the contributions identified may well resonate with others in a similar situation, therefore the specific characteristics of the participants who provided statements do not detract from the contribution this research has made.

The knowledge of the 'S' group participant demographics in particular were very limited and race and ethnic origin were not declared in any statement. However, all face to face interviews conducted collected information on demographics, including age and ethnic origin which confirmed that all interviewed participants were white British. The researcher acknowledges that this is not representative of the UK as a whole. The researcher also acknowledges that cross-cultural bias may have been present in the research, and that the finding of this research may not be applicable to others with different cultural norms.

As previously stated, demographic information was only collected for the participants subject to face to face interviews and the age of participants where statements had been given was only available if it had been disclosed as part of the statement. Of those participants their ages ranged from 42 years to 88 years. The researcher believes that this is a reasonable representation of informal carers as a whole in the UK but acknowledges that participants of a younger age may have had a different experience of the caring role and its effect on identity. A further limitation of the participant statements is that, by definition, statements do not provide such a rich source of qualitative data as do interviews and the intersubjectivity applied to these statements was of course extremely limited.

All participants were recruited from the same northern England geographical location of Hull and East Yorkshire. Potentially the experiences of participants

residing in this area may be dissimilar to those of others residing in alternative geographical locations.

In four cases, the interview with the carer took place in the company of the cared-for (described in chapter 3). This may have potentially affected the level of communication and disclosure in these interviews.

As previously stated, the researcher attempted to research the topic with an inter-subjective, second order dialogic standpoint (Cunliffe, 2003). This involved the construction of meaning between the researcher and the participant. Kvale, (1996), in his *"six step to data analysis"* advised a fifth step of re-interview once the interview had been analysed and interpreted in an effort to comment on those interpretations made by the researcher, but also to expand on any aspects of the original interview. This was attempted by the researcher, but through death, embarkation etc. a number of participants were lost to follow up. The authors of the 12 statements used in the research were also unable to be contacted (due to the anonymity of the data) and so re-interview was unable to take place.

Chapter 7. Conclusion

7.1   Contribution

7.1.1   Management contribution

7.1.2   Theoretical contribution

7.2   Areas for further research

This chapter concludes the thesis by illustrating the research problem and why further research in this area is required. The research aim and objectives are reiterated and confirmation that they have been met is provided. The chapter then provides a brief summary of the findings of this work and demonstrates how what has been discovered is an important and original contribution which will make a real difference to the lives of carers and has implications for a number of different sectors. The chapter ends with a suggestion of areas for future work.

The introduction chapter to this thesis included the quotation "A carer is what you do, not who you are" (Lola, Carers UK Forum, 2007). This thesis is about understanding how the concept of distance affects carers' perception of self-identity and how they feel about identity changes associated with caring, and what this means for them; to understand the process by which self-identity changes occur. Only by understanding their experiences can we can hope to learn about the carer transitional identity process and provide mechanisms to make things easier for them.

Extant literature has demonstrated widely publicised issues with informal caring – the number of carers are growing (and are expected to reach 9 million by 2037 (Carers UK, 2017)) and formal care provision is falling (Age UK, 2012). Informal carers are therefore often the only option to many elderly and infirm individuals requiring care.

Carer experiences, through the eyes of the carers themselves has not been subject to a great deal of research, particularly in academic fields. However the potential negative consequences of providing informal care are well documented (Schulz and Sherwood, 2008). Carers suffer from loneliness and isolation (Carers UK, 2017) and the burden they carry is often linked to feelings

of loss of their previous identity – that carer burden is associated with the carer's perceived necessity to change their lives when they have no real desire to do so (Bevans and Sternberg, 2012).

There exists a need to understand how carers manage the change in identity to help this transition. We need to understand their needs, and the constraints and tensions in their role so we can help ameliorate the problems associated with informal caring.

The literature has shown that already a lot is known about carers – who they are, what care they provide and how they do it, but there is little literature which has examined their experiences from the perspective of identity, and scant research that has considered the conceptualisation of distance and how it affects identity.

In response to this, the aim of this thesis was to understand how individuals transition from their previous identity to that of an informal carer, through the attainment of two objectives: Firstly, to understand the impact of distance on the informal carer identity and its relationship with others; and secondly to understand the transitional process associated with self-identity when informal care provision commences or changes.

This research has produced a number of novel findings in the search to understand the carer experience through the response to the following research questions:

1. How does the caring role affect carers' perception of identity?
2. How do carers feel about the changes to their self-identity?
3. How does distance affect the caring role?
4. What mechanisms are available to help carer self-identity transition?

In conceptualising distance this research has identified four types of distance that affect carer identity. Investigation of geographical distance demonstrated that in the study areas, differences between carer experiences in rural and urban regions were not distinctive. Further, the research revealed that carers have an optimal geographical distance between themselves and their care recipient, supporting (Hamon, 1992) but that this was dependent upon the

individuals' own circumstances. Geographical distance between ECE members was found to be linked to self-identity, with increased proximity suggesting a greater transition to a full carer identity, particularly in those carers that reside with their care recipient. This was closely linked to emotional distance and for those carers, a need to create personal space was identified (even within the same house, or even same room), as a way of attaining both physical and psychological distance from the carer identity. Tools were found to assist in achieving optimal geographical/physical distance including certain possessions such as cars, telephones and white goods which also linked to the alteration of social and emotional distance.

The second conceptualisation of distance identified was that of psychological distance. This distance in essence, was the need for carers to get some head space away from their caring identity and was often utilised when other forms of distance could not be achieved (in particular geographical/physical distance). Carers used tools such as pastimes (Sudoku, crosswords, card-making) in an attempt to utilise their minds in alternative ways to achieve both intellectual stimulation, but also psychological distance from their caring identity and thus, their care recipient. Limited research has been conducted on intellectual/psychological stimulation of carers prior to this, and no research known has conceptualised this as a form of distancing related to self-identity. Psychological distance attainment for carers often involved the pursuance of former hobbies, which had been lost in the transitions already undertaken towards the carer identity. Re-uptake of former hobbies achieved psychological distance but also often resulted in identity transitions back towards that of the former identity, altering social and emotional distance. In this way, objects, possessions and activities were often incorporated into self-identity to extend the self (Belk, 1988) away from the carer identity.

The third conceptualisation of distance was that of social distance which comprised aspects of all other concepts of distance. The importance of socialisation in extant research is not well understood and centred on reducing loneliness and isolation. Research has yet to link social inclusion (or lack of) to self-identity transitions in carers. Continuation of previously enjoyed social aspects assisted identity transitions towards their previous identity, affecting the

level of emotional distance they felt to their previous life, however for some carers, the identity of carer allowed the development of new social outlets (such as carer support groups). The loss of social proximity due to identity transitions to that of carer (such as losing touch with former friends) was a source of deep sadness and discontent for carers and sometimes resulted in resentment of both the carer identity and the cared-for themselves. Possessions that acted as a conduit for social interaction (such as a caravan) were often kept, even if never used as they acted as links to previous identity (minimising emotional distance to the previous identity) and were integral to the extended self (Belk, 1988) and social rituals (such as holidays, trips out, parties etc.) were renegotiated as far as possible to ensure the continuation of the carers' previous identity, with the addition of caring as a role and responsibility, rather than a renegotiation of 'self'.

The final concept of distance identified was that of emotional distance. Because of restrictions on the production of this thesis, and the fact that many of the other distance concepts actually result in a form of emotional distance (as previously demonstrated) this concept was critical to the understanding of carers' experiences as they transition between identities. The majority of caring was performed by spouses who had no other ECE members they could use for backup, either because they had no other family members or because their offspring were too geographically spread to provide hands-on care. Major issues identified included competing demands for time and multiple roles of their identity and almost all participants desired a change in their identity, from 'being a carer' to 'performing caring duties'. This shows an important link between emotional distance and the renegotiation of self-identity.

The findings distinguished a number of important aspects regarding the transitions of carer identities in that the transitional process commenced because of a number of 'motivators', were aided by the use of a number of 'moderators' and resulted in a number of changes in self-identity as 'manifestations'. Motivations to change identity often occurred at the inception of informal care, when through duty and obligation (either to the care recipient or to other ECE members), carers felt the need (and most often not the desire) to add informal caring tasks to their existing roles and responsibilities. This

created an integral transition in their self-identity to include aspects of being a carer. Other motivators included a desire to increase emotional distance from their carer identity – to transition by degrees, towards their former identity. Motivators could also be considered via emotions which were specifically negative to the carer at that time such as loneliness, frustration, and feelings of being trapped in the carer identity. Conversely, some carers were motivated to transition identity towards that of a carer by decreasing emotional distance. This occurred due to feelings of guilt, concerns regarding existing care provision, the worsening condition or increasing needs of the care recipient.

Moderators were used by carers as tools to assist in the transition of self-identities through the manipulation of emotional distance. Such moderators included other ECE members to assist with the caring role and potentially 'share' the carer identity, or conversely bar other ECE members from becoming involved, thereby safeguarding the exclusivity of the carer identity. Possessions, objects and rituals also serve as moderators in the manipulation of emotional distance and the transition of self-identity. Often for carers, this meant the manipulation of possessions and the renegotiation of rituals for their care recipients to reduce emotional distance between them and their previous identity.

Manifestations are the outcomes or changes in identity resulting from the process of identity transition, assisted by the moderators and inspired by the motivators. Negative manifestations (seen through the eyes of the carers) were often related to the inception of caring. Behaviour changes, personality differences and feelings of frustration and resentment were not uncommon, particularly due to the feeling that the carers had not given permission for their self-identities to change (Aggar et al., 2011), and in participants who had ended employment or relocated their residence to provide care. Changes in roles and responsibilities were common manifestations of self-identity transition. Additional ECE members may become involved to share the burden of care, or reduce the care they provide, and carers may take on additional roles from their care recipient. The addition of the carer role and the resulting transition of identity was exacerbated in carers who already occupied multiple roles and identities (such as Mother, wife, employee etc.). The balancing of multiple

identities was a source of stress and frustration and often involved the wider members of the ECE. In these circumstances, carers often desired further renegotiation and transition of their identities, often using the wider ECE as moderators. The greatest sadness revealed by the findings was the loss of relationship identities with the transition to the carer, cared-for identities. As the wife, husband, Mother or Father became 'carer', the former relationship labels disappeared as a manifestation of caring identity adoption. These losses were not desired and caused great emotional pain for carers as their care recipient became a *"stranger", "another child"* or just the person I care for.

This research has developed a novel theoretical framework for the consideration of carer identity transitions, based on the manipulation of emotional distance. The conceptual framework confirms the existence of an optimum position for carer's self-identity, positioned on a continuum between their previous identity - life, activities, roles, responsibilities and relationships (PLI) and their caring identity - life, activities, roles, responsibilities and relationships (CLI). For each individual, their position on this continuum and the direction of desired transition is dictated by their own personal circumstances, desires and characteristics.

7.1. Contribution

Informal caring is becoming an issue of increasing importance in the UK, as population demographics change, resulting in a greater number of individuals suffering from ill health, disability and frailty. Extant research has demonstrated the existence of carer identities whereby labels of carer and cared-for are applied to self-identities, to a greater or lesser extent, depending on individuals circumstances. However, research had not considered the conceptualisation of distance, nor the process of transition in carer identities, what motivates changes in self-identity and how these changes occur. This thesis has addressed this gap in knowledge by identifying how carer's perceptions of identity change with the inception of informal care and how the carers feel about these changes. This research has demonstrated how distance affects carers and the mechanisms available to them to assist in identity transitions.

7.1.1. Management Contribution

This thesis has been conducted as part of the University of Hull Marketing department. Marketing is concerned with identifying and understanding the wants and needs of individuals (Kotler and Keller, 2012). This thesis provides an original contribution to the understanding of carers, as a group and as individuals. By illustrating and understanding the experiences of carers, how their identity may change and what this is affected by, this thesis provides an important contribution for marketers to identify the potential needs of this group.

Policy makers will also be interested in the contribution this research has made in terms of the issues that carers struggle with. The research has highlighted information which may be of particular interest to local authorities and wider Governmental sectors in considering future care provision in the UK and in particular, highlighting the reasons why, and methods that carers use to make themselves better carers and what additional support would be useful. This research provides a snapshot of the experience of carers in Hull and East Yorkshire. One of the biggest areas of frustration described by carers was the lack of support they felt from formal authorities, despite in the minds of the carers at least, providing care which the authorities has failed to do. The research provides insight into the costs of being a carer, both financially and

emotionally and this greater understanding should appeal to policy makers in attempting to ensure the mental and physical health of carers, - their unseen and unpaid workforce. This is turn may assist to manage the elderly population caring needs whilst a shortfall in formal care exists. This work may also provide a suggestion of value in the collaboration of authorities and informal carers, but also voluntary services and community groups. Contemplation of revised policies regarding tax breaks for carers, carer allowance revisions and other forms of investment in informal carers may also be beneficial.

Third sector and voluntary organisations may find the contributions of this research useful to offer targeted support for carers and those they care for, in the issues identified by this research. Findings confirmed feelings of isolation and particularly showed the problems that the carers in this research experienced in attaining any kind of break from their caring which may be of interest to the third sector. In this way, this research responds to the call by Allen et al., (2012) to broaden our understanding of transitions in informal care to assist families in filling the gap between care need and formal care provision.

This work also contributes to insights which may prove useful to existing carers and care recipients regarding practical measures that may improve the real-life experience of those involved in informal care. This thesis may provide an opportunity for carers to learn from each other in a number of ways. This work may help carers feel less isolated and more connected to other carers through the format of shared experiences – to learn that the struggle they themselves face is similar to the struggles faced by other carers. Lines of commonality between themselves and other carers may also assist in a real, practical way to learn from the experiences of other carers. This could potentially include providing practical tips and handy hints which can be put to use in their own caring relationship. Finally, this work may help carers in their own relationships by providing a description of the process by which identity transitions in carers and by firstly acknowledging that a transition may indeed take place. This research highlights examples of moderators or tools which can be used to alter the relative emotional distance experienced. This in turn can then be used in achieving the optimal position for that individual. This research therefore, can be

used to help equip carers with the tools they need to alter their own position on the identity continuum – providing real benefit in the lives of carers.

The research provides a clear understanding of some of the issues facing informal carers today. Problems identified such as the ability to take a break from caring, issues with holidays suitable for disabilities, problems with grocery shopping etc. may be of interest to industry. The development of new goods and services to tackle problems such as these may be of real benefit to carers. The importance of white goods was also highlighted in the research and supports the suggestion that they potentially hold greater importance to carers than other groups as they allow "arms-length caring", freeing the informal carer to limit their identity transition.

7.1.2. Theoretical Contribution

The findings of this research provide a theoretical contribution to knowledge through the novel consideration of the concepts of distance and the transition of carer identities. Theoretical contribution should consider originality and utility– an original insight into a concept which advances knowledge which can then be used for a specific purpose (Corley and Gioia, 2011). Corely and Gioia, (2011) suggest that theoretical contributions can demonstrate either incremental or revelatory originality and either practical or scientific usefulness, but confirm that work must be interesting and surprising if a significant theoretical contribution is to be interpreted from the work. This research has conceptualised the transition of carer identities by recognising a number of motivations that dictate a desire for change in the self-identity of carers and also, a number of tools used by carers to bring about these changes, and producing a framework to describe it - providing an original contribution to theory. This framework provides a novel interpretation of the transitional process of carer identity, and fills the gap in knowledge by identifying what this process is affected by, and explaining how it may occur. Using real-life examples of the process in action, this research has been able to expand of what is already known about carers and how they deal with the rigours of their role, manage change and what tools they use to assist their identity transition.

This research also identifies other gaps in understanding identity transitions, for example the identity transition which care recipients undergo, which is explained more fully in the next section.

This research partly addresses the call by Hubert and Hollins, (2000) for research to consider the joint and individual needs of elderly carers and care recipients, and Stephens and Franks, (1999) call for further research into the multiple roles and competing demands of carers. This research has demonstrated that many of the carers included in this research found the balancing of multiple roles difficult. However, the research also demonstrated that multiple roles effect emotional distance and identity transition (Edwards for example, described himself as a tree with many branches that he felt he must distribute evenly). This research also addressed in part the call by Creese, (2003), McKenzie et al., (2010) and Tommis et al., (2007) to consider differences in rural and urban caregiving. This research found that within the specific population considered, there were few differences, supporting Dwyer and Miller's (1990) claim that caregiving cannot be considered on the basis of a residential continuum.

The work has already contributed to providing a theoretical contribution, through the publication of the academic paper "Physical and emotional nourishment" in the European Journal of Marketing (2018, 52 (12)) which considered the intergenerational relationships and the role of food as the elderly transition into requiring care. Other areas to be explored directly from the data of this research include the role of men as carers and investigation of the liminal phase of identity transition.

7.2. Areas for Further Research

The original premise of this research was to identify and investigate the concepts of distance which affect informal carers. To that end, the data identified the four concepts previously stated. However, time and word count restrictions meant that only the concept of emotional distance could be fully utilised in developing theory regarding how carer identities transition and why. Further research into the concepts of geographical/physical distance, social distance and psychological distance would be very useful and may reach across disciplines such as health, social sciences and psychology as well as marketing.

This research did not consider specific carer groups as focus was on the holistic experience of carers and their self-identity in general. Different carer groups may have specific experiences not shown in the findings of this research, therefore future work may consider disease-specific carers (e.g. carers providing care for dementia sufferers or stroke victims). This research targeted carers of any age, caring for elderly individuals of over 65 years. Further research may also like to consider the experiences of alternative age groups in both the age of the carer and cared for, such as the experiences of young carers, or those of any age that care for young children and adolescents.

The original premise of this research was to identify and consider the differences in carer experiences in rural as opposed to urban populations with regards to emotional distance and identity transition, however found few differences in the data. Nonetheless, extant literature and the findings of this research may suggest that some differences do exist in other areas of the carer experience; specifically in terms of care recipient expectations of level and type of care, frequency of contacts etc. and the consumption patterns of urban versus rural care recipients, with particular focus on the purchasing and utilisation of white goods.

The focus of this research was self-identity changes among carers, however a certain number of care recipients were also interviewed. The findings from these participants highlighted the possibility that care recipients also go through self-identity transitions similar to carers which may provide a basis for useful

research in the future. Of particular focus could be the consideration of the tensions which result when two identities are transitioning at the same time.

The participants included in this research were mostly active carers of a family member. However a small number of participants were ex-carers after the demise of their care recipient. The research concentrated on the identity transitions which occurred whilst care recipients were alive, with particular focus on changes that occur with the onset of caring. However an interesting area for further study would be consideration of carer self-identity transitions after the death of the care recipient.

This research provided a rich dataset for the examination of decision-making and agency in care relationships. The participants of decision making in elderly care recipients and the group dynamics involved in those decisions was of great interest, although not the focus of this research. However, decision-making and links to self-identity changes were also recognised, but beyond the scope of this thesis. Further investigation on this topic may prove valuable, particularly building on existing research regarding decision-making in informal care relationships.

A further limitation of this research identified was that of the potential for cross-cultural bias, due to the research participants being exclusively white British. The culture of providing informal care may well be different in different countries, or even within specific populations. It would therefore be beneficial for future research to consider identity transitions in informal carers in other cultures, with specific emphasis on whether the theories identified by this research remain applicable in families who are not exclusively white British.

This thesis started with a quote from a newspaper which confirmed that carers were 3 times more likely to commit suicide than the normal population – the issues affecting carers are very real and very serious. Headlines that highlight the plight of informal carers are sadly not uncommon and are likely to continue as the number of informal carers grows. Research such as this thesis, research that attempts to understand the experiences of carers, how they manage their lives and their very identity, is of great importance in efforts to improve the daily living of carers. There is a continuing need to ensure that their needs and wants

are identified and to inform others in the hope that their situation can be improved; it is hoped that this thesis contributes to fulfilling that need.

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