

Moral Distress in the Care of People Living with  
Moderate to Advanced Dementia: A Narrative  
Exploration of Family Carers' Experience of Home-  
Based Care Provision towards the End of Life

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I declare that this thesis is my own work and has not been submitted for the  
award of a higher degree elsewhere

## Published work

Some aspects of this research have been published during the conduct of the study. All are the original work of the author.

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## **Abstract**

### **Background**

The number of those living with, or providing care for, those with dementia is increasing, projected to quadruple by 2040. Around 700,000 people currently provide unpaid care in the UK to those with dementia. However, knowledge about what it is like to provide such care in domestic home settings for those in the moderate to advanced stages of dementia is limited, especially towards the end of life. Where experiences are known, they are usually described in terms of psychological distress, internal conflict, and powerlessness. One concept that has proven helpful in research with paid carers such as nursing staff is that of moral distress, and it may be that this is also an issue for unpaid or family carers.

An initial systematic review with narrative synthesis explored caregivers' accounts of their experiences within the domestic home setting caring for people with dementia. Caregivers' account of experiences related to a description of burden, loss, grief and how they deal with challenges while caring for someone living with dementia. The conduct of this empirical study was informed by the results of the review.

### **Research question**

What are the narratives of care provision by family carers, and how do they describe their experience of home-based care for people with moderate to advanced dementia towards the end of life?

### **Design and methods**

A narrative inquiry design was adopted using unstructured interviews with family carers for people living with moderate to advanced dementia and cared for within a domestic home setting. Participants were purposively selected and recruited through UK organisations offering services both to the family carers and the care recipient. A narrative technique was employed in data collection and a textual narrative approach was adopted in analysing the data.

### **Findings**

Fifteen participants took part in this study. Their narratives were presented under five headings of loss, control, role change, coping and help-seeking. Their experience of moral distress was moulded by the internalised conflicts encountered in caregiving.

## **Discussions and conclusions**

Caregivers experienced role transformation as an unanticipated response to the dementia diagnosis of the person they cared for. This transformation makes the performance of a perceived moral duty difficult, and hence a reason for the reported feeling of powerlessness. The moral distress was experienced at the point of the necessity of a moral course of action during the fulfilment of the caregiver's perceived moral duty. A policy on stage-specific post-diagnosis support for unpaid home-based caregivers is necessary for reducing the unsuitability of support received within the moderate to the advanced stages. Interventions for alleviating the impact of caregivers' negative experiences at an early stage of the transformed role is also necessary. Further research is, however, necessary to explore whether increased internal conflicts may lead to an increment in caregivers' moral distress.

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# Chapter 1: Introduction

## 1.1 Background

Dementia is a collective term for describing symptoms or conditions that cause progressive deterioration of cognitive abilities and everyday functional capabilities of a person (Kumar et al., 2020; Chertkow et al., 2013; Grand et al., 2011). Alzheimer's disease is regarded as one of the most common causes of dementia (Alzheimer's Association, 2017). There are a range of dementia-type illnesses, such as Lewy body, frontotemporal, vascular, and mixed dementia, although other types exist (Karantzoulis, 2011). In 2014, 1 in 14 of the population affected were aged 65 years and over, with a further 40,000 people under the age of 65 who were known to be affected by dementia (Knapp et al., 2014). By 2019, it was reported that over 850,000 people were living with dementia in the UK (Wittenberg et al., 2020; 2019). By 2040, it is further projected that the overall number of people aged 65 and over with dementia in the UK will be around 1.6 million (Wittenberg et al., 2020; 2019). A cure or an effective prevention for dementia is currently absent and is considered a syndrome of increasing public health concern (Livingston et al., 2020).

Receiving a diagnosis of dementia is often difficult and sometimes described in terms of a feeling of shame and loss of oneself (Xanthopoulou & McCabe, 2019; van Gennip et al., 2016; Aminzadeh et al., 2007). There are often social implications for the people diagnosed and their families (Lee & Weston, 2011). Life expectancy in dementia is unpredictable in comparison with other terminal diseases, such as cancer (Vestergaard et al., 2020; Hall & Sikes, 2018; Arcand, 2015; Harris, 2007). Being diagnosed with dementia is often regarded as a burden which increases the level of uncertainty about the future for both the person with the disease and their family (Galvin & Sadowski, 2012; Phillips, 2011). Life expectancy also varies between individuals, although a duration of less than 10 years after diagnosis is regarded as a

common assumption (Joling et al., 2020). As such, the duration of caring for someone with dementia is likely to last longer than in most other terminal illnesses.

The level of decline in dementia is often identified through stages, representative of the degree of severity. These stages are usually defined from the early to the most severe level of decline (Alzheimer's Society, 2015; Schmidt, 2014; Auer & Reisberg, 1997). The severity of the stages is often described by the decline of self-care activities of daily living, such as dressing, bathing and toileting by the person diagnosed (Kumar et al., 2020; Mlinac & Feng, 2016; Marshall et al., 2012).

Progression within the stages is common over time, although the degree of decline in people with dementia varies (NICE, 2018; Clemmensen et al., 2016). Some of the symptoms associated with decline may be experienced differently across these stages (NICE, 2018; Clemmensen et al., 2016). While these may be experienced earlier or later by some people, or not at all by others, it is also possible for stages to overlap (Alzheimer's Society, 2015).

This thesis did not involve objectively assessing the severity of dementia. The use of the terms, moderate and advanced, reflected participants' own narratives, which were usually informed by their conversations with health and social care professionals. The symptoms of decline within the moderate to advanced stages of dementia are well-documented. For instance, a progressive functional decline is likely to be experienced by the care recipient within the moderate stage (Kerpershoek et al., 2018; Cheng, 2017). The progressive nature of dementia within this stage, and towards the end of life, suggest the possibility of an overlap of symptoms likely to result in staged experiences for the family carer. This further suggests that the family carer's input in care provision is likely to also increase in line within this stage.

Functional decline may also be experienced from an earlier stage. Care recipients' participation in activities of daily living such as washing and feeding

may still be possible (Jutten et al., 2017; Alzheimer's Society, 2015). However, the variation in the degree of decline also affects the level of individual capability within the moderate stage (Clemmensen et al., 2016; Alzheimer's Society, 2015). This suggests a likelihood of a variation of experiences of individual caregivers within this stage.

Increased incontinence or deterioration of both bladder and bowel control for people with dementia may signify an advanced decline as the condition progresses. This may be influenced by an increase in memory deficiency and the level of confusion, which often increases in severity through to the end of life (Mitchell, 2015; Alzheimer's Society, 2015; Bardsley, 2014). Behavioural changes commonly associated with the moderate stage are also possible (Alzheimer's Society, 2015). These behavioural changes, such as increased agitation and anxiety are regarded as a sign of advanced decline (Alzheimer's Society, 2015). Hence, the advanced stage is likely to signify a progression through the dementia trajectory, which also indicates that the person with dementia may be approaching the later stages where end of life care may become necessary.

The number of people with dementia who require end of life or palliative care is projected to grow four-fold by 2040 (Etkind et al., 2017). The timing to the end of life remains unpredictable (Hendriks et al., 2014), and the nature of dementia itself may increase the uncertainty towards the end of life. There is, however, a likelihood that better understanding of the progressiveness of symptoms at the advanced stages may be a useful guide to improvement of care provision (Kupeli et al., 2019). It is considered that the symptoms from previous stages such as incontinence and behavioural changes are likely to be more severe in the later stages (Kupeli et al., 2019; Sampson, 2010). Although other symptoms at this later stage are also common, such as frailty and decreased mobility (Alzheimer's Society, 2017; Sachs et al., 2004), increased behavioural changes are, however, regarded as the most

common predictor of advancement and possible institutionalisation during this stage (Sampson, 2010).

## **1.2 Family caregiving within the domestic home setting**

The domestic home setting often represents a place of familiarity, safety, comfort, and security (Calkins, 2018; Mogan et al., 2018; Fleming et al., 2015). In this present work, this represents the specific domestic environment where the person cared for resides primarily. It differs from other care provision establishments, such as care homes, where paid care may be provided. In the UK, care for people living with dementia is commonly available in institutions such as care homes, hospices, and hospitals (Dixon et al., 2019; Sleeman et al., 2016; Badger et al., 2007). Dementia is prevalent with majority of people who reside in UK care homes (NIHR, 2020; British Geriatrics Society, 2016; Knapp et al., 2014). A preference for a home-based or informal care is however expressed by most of these people, as well as their family especially at the later stages (Mogan et al., 2018; Lord et al., 2016). In this thesis, references to home-based care signifies caregiving within a domestic environment where the care recipient resides.

Family carers who may or may not co-reside with the care recipient are the family members, friends, relatives, or anyone who provides unpaid but significant care (Lindeza et al., 2020; Evans et al., 2019; Woodman et al., 2016). They are also known by other terms such as informal caregivers, informal carers and care partners. Throughout this present work, they are referred to as family carers for conciseness. Given the long hours spent providing care for people with dementia, they are regarded as the invisible second patient due to their own care needs but are often crucial to the quality of life of the care recipient (Karg et al 2018; Sanders, 2016; Brodaty & Donkin, 2009).

An estimated 700,000 people provide care informally to the people living with dementia in the UK (Lewis, 2014). Their duties within the caregiving role vary according to the needs of the person with dementia and usually increase in line with severity (Mesterton et al., 2010). Some of these duties involve the provision of hands-on care such as helping with getting dressed, toileting, feeding, financial support, and assistance with other daily living tasks (Plöthner et al., 2019; Brodaty & Donkin, 2009). In 2019, around 36% of family carers spent more than 100 hours per week caring for someone with dementia, and about 40% provided round-the-clock care (Dementia Carers Count, 2019). Some difficulties are, however, experienced by the family carers given the unpredictability of dementia (van Wijngaarden et al., 2018; Schulz & Eden, 2016). This long trajectory of dementia therefore suggests that these difficulties are likely to increase the burden of caring for some caregivers.

### **1.3 Home-based caregiving challenges**

Most people with dementia are often cared for within a domestic home setting by their families, both in the UK and internationally (Evans et al., 2019; Brodaty & Donkin, 2009). Although experiences of difficulties and burden of caregiving especially towards the end of life are reported (Schulz & Eden, 2016), most family carers view their role with a sense of satisfaction at facilitating a good end of life for a family member (Brodaty & Donkin, 2009; Treloar et al., 2009). This may be due to the care recipient's expectation of a quality care provision at the end of life or a regard for home as a place for a good death (Mogan et al., 2018). It may also be due to the likelihood of a home-death while being cared for informally (Murtagh et al., 2012).

Fulfilling a home-based care wish towards the end of life often relies on the willingness of a family carer to take on the role. Whilst in some cases, such care provision may be viewed as the caregiver's choice (Al-janabi et al., 2018), the assumption of the role is mostly associated with a lack of choice (Pertl et al., 2019; Reinhard et al., 2012; Schulz et al., 2012). This lack of choice and the long hours

spent caregiving may increase caregivers' burden and depression (Greenwood & Smith, 2019; Karg et al., 2018; Schulz et al., 2012). A view of family caregiving as performing a moral obligation is therefore plausible. Reports of psychological distress have also been given, which Borsje et al. (2016) suggest as the major driver for possible consideration of care recipients' placement in other care environments outside the domestic home setting. Shah et al. (2010) also highlight that when these experiences become unmanageable, institutionalisation is usually considered in most cases, especially in later stages of dementia.

Caring towards the end of life may lead to the family carers' poor quality of life (Lindeza et al., 2020; Karg et al., 2018; Brodaty & Donkin, 2009). Studies have demonstrated that it is more stressful to care for someone with dementia. As the care recipient's functional decline increases especially from the moderate stages, behavioural changes, such as aggression are likely to intensify (Müller-Spahn, 2003). Such behaviours are unpredictable in nature and considered more stressful for the caregivers than challenges associated with both cognitive and functional decline (Ornstein & Gaugler, 2012). As possible predictors of caregiver burden and depressive symptoms (Cheng et al., 2012; Ornstein & Gaugler, 2012), these behaviours are also likely to cause psychological distress and increase the negative impact of caregiving on physical wellbeing (Van der steen et al., 2017; Kokorelias, 2016; Borsje et al., 2016). This suggests that psychological distress may be higher for people caring for someone with dementia than for non-caregivers.

A feeling of powerlessness in making changes to the caregiving situation is often experienced by family carers (Anderson & White, 2018; van Wijngaarden et al., 2018; Hamdy et al., 2017; Davies et al., 2014; Day & Anderson, 2011). Some associate this with their frustration at the care recipient's behaviours (Massimo et al., 2013), whilst a lack of control over the disease trajectory is often cited by others (O'Shaughnessy et al., 2010). Feelings of anxiety, guilt and anger are also common (Morris et al., 2018;

Lamahewa et al., 2018; Swallow, 2017; Smebye et al., 2016). Accounts of similar experiences have also been given by non-family caregivers (Morris et al., 2018; Milne, 2018). While these accounts are often described in terms of internal conflicts and moral distress, commonly described as when one knows the right thing to do but unable to effect any changes (Milne, 2018; Morris et al., 2018; Fumis et al., 2017; Borhani et al., 2014), the experiences of moral distress of family carers for people with dementia within a domestic home setting are yet to be investigated.

#### **1.4 Moral distress and internal conflict**

The exploration of moral distress and internal conflict in this present work is premised on a framework developed from the variation of definitions used to describe the concept of moral distress. As a terminology first used by Andrew Jameton in 1984, moral distress is described *“when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action”* (Jameton, 1984, p6). It has also been described as an occurrence when *“one knows the right thing to do, but institutional or other constraints make it difficult to pursue the desired course of action.”* (Raines, 2000, p.3). For Hamric and Blackhall (2007, p.423), moral distress happens *“when the practitioner feels certain of the ethical course of action but is constrained from taking that action”*. Epstein and Hamric (2009, p.330) consider it an occurrence *“when one knows the ethically correct action to take but feels powerless to take that action”*. Other definitions also exist (Morley et al., 2019; Rushton et al., 2013; Corley et al., 2001; Lützén et al., 2003), although no single definition was considered more important than the other.

Moral distress is usually framed within the ideologies of an institution, constraints, and professional boundaries. Over the years, many proponents of moral distress have highlighted the inability to perform an ethical action as being influenced by constraints imposed either externally through institutional boundaries, or internally through self-defined factors, such as anxiety (Hamric et al., 2006; Jameton, 1993).

The exploration of its varied definitions establishes a pattern by which the concept is most commonly understood. It was therefore crucial to draw a reference from the initial definition of moral distress by Andrew Jameton (1984, p6).

It is recognised, however, that the initial definition by Jameton (1984) was based on reported experiences of nurses within clinical environments and demonstrates that moral distress may be bound by a defined set of rules or beliefs within clinical environments. It is possible that moral distress is identified where a set of rules or beliefs contradict individually held rules or beliefs within a defined environment. It is also likely that more focus is given to moral distress as a reaction. Some critics have however identified the limitation of understanding in the definition of moral distress by Jameton (1984). According to Hanna (2004), the challenged ethical principles and the external constraint causing distress are insufficiently addressed. While constraints may lead to distress, Fourie (2017) argues that it is not the only factor that causes moral distress within a clinical environment. Moral distress may also be viewed in terms of morally difficult situations unrelated to uncertainty or constraint (Campbell et al., 2016; Fourie, 2015). It is possible, therefore, that the concept of moral distress extends beyond the traditional meaning of an institution. The relevance of the concept of moral distress in terms of its role in underpinning the theoretical framework for this thesis is further explored as a moral distress triangle framework.

#### **1.4.1 Moral distress triangle framework**

The consensual view of moral distress stems from Jameton's (1984) understanding, as a concept widely explored within the experiences of nurses in clinical environments (Kälvemark et al., 2004). This perception of moral distress as an experience within professional or clinical environments is the premise on which the development of the moral distress triangle framework is based in this present work. North (1990; 1996) argues that environments such as these may be considered

within the meaning of a traditional institution, in which a set of formal rules act as constraints (such as laws or constitutions), or informal rules (such as conventions, norms of behaviour and self-imposed codes of conduct), that structure human interactions. Hence, the definition of moral distress as, "*when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action*" (Jameton, 1984, p6), could be considered as an appropriate foundation for understanding within these environments.

A consensus on the definition of an institution is difficult (Lu, 2015; Hollingsworth, 2000). According to Gagliardi (2008), its meaning may depend on the purpose of the analysis. Different meanings have been attributed within different contexts (Jackson, 2010; Mehta et al., 1999). The meaning of an institution may be understood in terms of established rules, beliefs, and social interactions (Hodgson, 2006; Greif, 2005). An institution may also be regarded as "*systems of established and prevalent social rules that structure social interactions*" (Hodgson, 2006, p2). It is likely therefore that other structures with individually defined rules and set of beliefs, such as family, religion and a domestic home may also be appropriate within the wider meaning of an institution. Similarly, consideration of a possible experience of moral distress by caregivers in such informal settings may also be appropriate within the wider meaning of an institution.

Over the years, contemporary discussions have successfully recognised that contrary to the initial belief that moral distress only affects nurses, its experience may also be a phenomenon common amongst people working across a wide range of professions and environments (Fourie, 2017; Epstein & Delgado, 2010; Ganske, 2010). For instance, the experience of moral distress has also been explored in the context of education (Monrouxe et al., 2015; Ganske, 2010), and social work (Openshaw, 2011). Within these contexts, the experience of moral distress is predominantly

described as a negative phenomenon, in similarity to reported accounts within clinical environments. It is also clear that regardless of the setting where its occurrence is explored, majority of the focus on its experience to date only go as far as addressing its influence within the same intrinsic pattern as Jameton's (1984) initial understanding grounded within the nursing profession.

A body of work conducted into moral distress across a variety of settings refined the definition of moral distress as a phenomenon in which one knows the right action to take, but is constrained from taking it (Dudzinski, 2016; Epstein & Hamric, 2009; Ganske, 2010; McCarthy & Deady, 2008; Corley, 2002). Through this lens, moral distress appears to be recognised as an experience not restricted to institutional constraints (Kälvemark et al., 2004). It is possible to consider that over the years, a better understanding of the wider meaning of an institution influenced the exclusion of a setting from its common definition. Recent studies by Morley et al. (2019) and Browning and Eckel (2018), however, show that an attribution of moral distress experience to institutional settings however remains a restrictive feature in its description.

The attributes of moral distress show that three key assumptions continue to be used in the exploration of its experience. First, there is a '*person*' who '*knows the right course of action to take*'. Second, the person works within a '*capacity*' or setting. Third, the *setting* is bound by a set of rules or codes of conduct, in a clinical environment, for instance. It is possible that an expectation exists for knowledge of the setting to increase with time within this person's capacity. It is also probable that a better understanding of the setting is expected over the same period. These assumptions continue to be adopted in describing the experience of moral distress regardless of the setting. For example, Openshaw (2011) describes moral distress as

a phenomenon where a social worker encounters an ethical dilemma between social work policies and what the social worker believes to be the right course of action.

Much emphasis is placed on the *'person'*, who *'knows what to do'*. Consideration for how knowledge is created is however limited. A challenge therefore remains in understanding the meaning of moral distress where the knowledge of what to do becomes difficult, such as in cases of a caregiver's uncertainty of a course of action, or in settings where rules are less defined. To understand whether the experience of moral distress may be possible beyond the current understanding, four philosophical questions were posited (see Fig 1.1):

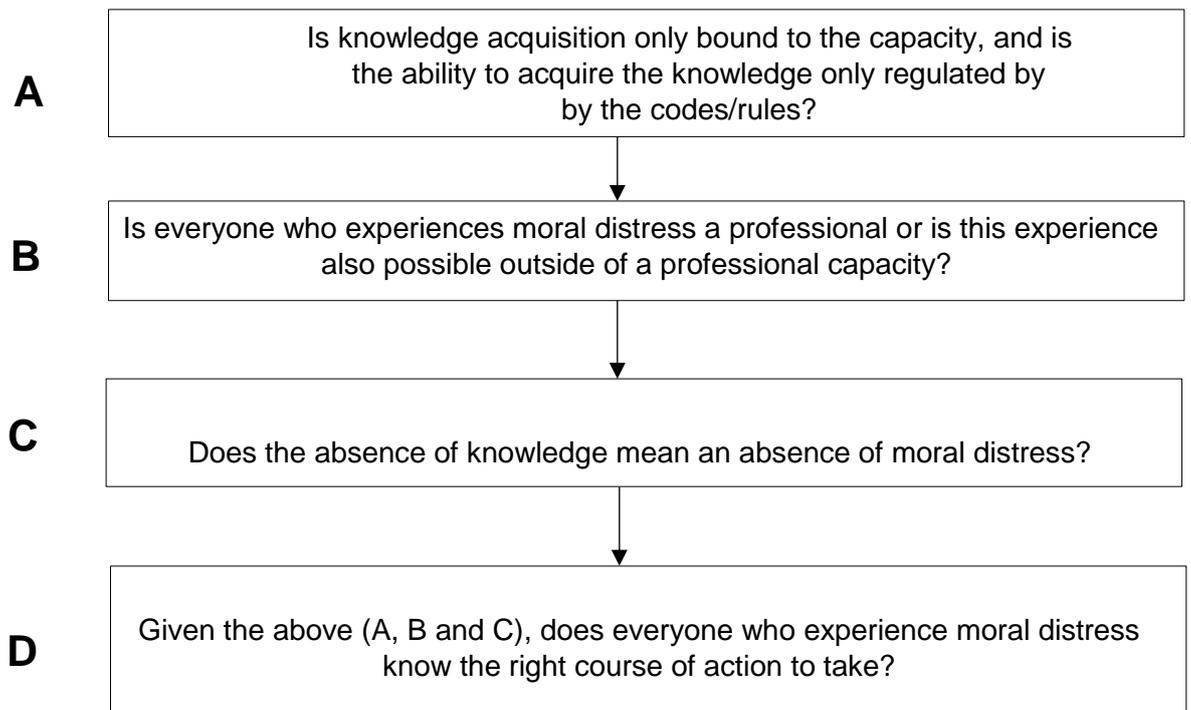


Fig 1.1: Moral distress flowchart

People who provide care informally in settings such as a domestic home, also report feeling conflicted internally (Dombestein et al., 2020; van Wijngaarden et al., 2018). Their feelings are often described in terms of an anger, anxiety and frustration, whilst experiencing an uncertainty in what to do (van Wijngaarden et al., 2018). Family carers have also reported a feeling of powerlessness to change their situation (van

Wijngaarden et al., 2018). Within these informal settings, knowledge acquisition is possible. Indeed, Lindeza et al. (2020) argue that acquired knowledge may improve the quality of care provision and help in preparation for specific situations. Some caregivers however consider their feeling of powerlessness as being associated with their knowledge of the care recipient (van Wijngaarden et al., 2018). Others also relate these feelings to an uncertainty in knowing what course of action to take (Lloyd & Stirling, 2011; O'Shaughnessy et al., 2010). It is therefore likely that internal conflict or moral distress may also be experienced by non-professional caregivers within these settings.

Most knowledge is acquired from experience. Moreover, the ability to experience is natural (Williams, 2018). It is a common assumption that the acquisition of relevant knowledge within a professional capacity is achievable only within the specific boundaries of its structure. This view may be limited in scope, however, as the possibility of experiences such as moral distress occurring outside the familiar boundaries of a defined structure, such as a domestic home setting has not been considered. This also offers a limited scope in understanding moral distress as a phenomenon, given that the ability to reason, make decisions or acquire knowledge is a connatural virtue of any persons within any environments.

The current understanding establishes moral distress as a phenomenon whereby one knows the right action to take, but is constrained from taking it (Dudzinski, 2016). From these discussions, this premise may also assume the necessity of a duty for knowledge acquisition. The consideration of moral distress also as a phenomenon that not only exists as a result of the inability to act due a constraint, but also in realisation of the necessity of an action is also possible. If this assumption is true, moral distress may not be viewed as a reaction as suggested by the inability to act due to a constraint, but a wider issue for knowledge acquisition and the necessity of an action.

## **1.5 Research question, aims and objectives**

The focus of interest in this study was to understand the experiences of family carers who provide care for people with a moderate to advanced dementia within a domestic home setting. The following question was proposed: *“What are the narratives of care provision by family carers, and how do they describe their experience of home-based care for people with a moderate to advanced dementia towards the end of life?”*

In addressing this question, three research objectives (RO) were set as follows:

**RO1:** To identify whether, and how family carers describe internal conflict as part of their experience of end of life care provision for people with a moderate to advanced dementia.

**RO2:** To determine whether family carers’ description of internal conflict signifies the experience of moral distress.

**RO3:** If present, to describe the narratives of caring that family carers have about internal conflicts leading to moral distress.

## **1.6 Thesis structure**

Exploration of the experiences of family carers for people with a moderate to advanced dementia cared for within a domestic home setting is presented over seven chapters in this thesis. As the researcher, my professional role involves frequent conversations with families of people with dementia, who sometimes provide care within the domestic home setting. The structuring of the thesis is influenced by the experience gained within this role, and the contents of the individual chapters of the thesis are summarised as follows:

This current chapter has outlined the overall background concepts that inform the study conduct. The establishment of the domestic home setting as an institution was undertaken as well as the exploration of key terminologies such as family carers. The

different stages of dementia were identified, and clarification was made to show that the study is mainly focused on dementia within the moderate and the advanced stages. Furthermore, the aims and objectives of the study were identified. The meaning of moral distress and internal conflicts were also explored.

The literature review is presented in Chapter 2 following a narrative synthesis method (Popay et al., 2006). This method was adopted in synthesising and evaluating existing knowledge about family carers' experience of providing home-based care to people with moderate to advanced dementia. By synthesising findings from primary research, gaps in current knowledge are also highlighted on contexts of caregivers' perceptions of caregiving within a domestic home setting.

My philosophical approach and epistemological positioning are discussed in Chapter 3 of this thesis. The design and rationale for selecting the narrative inquiry technique as the methodological approach are also presented. Furthermore, the steps taken in ensuring rigour in the research process are discussed, thereby giving evidence of the appropriateness of both the methodology and methods adopted in answering the research question.

In Chapter 4, the research population, sample, and methods adopted for recruitment of study participants are described. A number of the difficulties encountered in recruitment and methods by which these were resolved are discussed. Routes for the identification of study participants are also explored, and the process by which collected data were analysed are also presented.

Chapter 5 focuses on presentation of the findings following the analysis of collected data. A narrative approach using a thematic analytical process developed by Riessman (2008) was adopted. The findings are presented under five narrative headings, generated through the use of participants' verbatim quotes and words from the analysis of their interview transcripts.

The findings and their interpretation are further discussed in Chapter 6. In this chapter, the research question is broken into two parts, “*What are the narratives of care provision by family carers?*” and “*how do they describe their experience of home-based care for people with a moderate to advanced dementia towards the end of life?*”. The discussions in this chapter are therefore undertaken in two parts focused on answering this research question.

The contribution of this study to current knowledge is considered in Chapter 7. The implications of the study for policy, practice and future research are also presented. Along with reflections on the strengths and limitations of the study, the overarching conclusion of the thesis is also presented which may inform how the needs of home-based family carers for people with a moderate to advanced dementia can be better met.

## **1.7 Conclusion**

The purpose of this study was to explore how family carers describe their experience of home-based caregiving for someone with moderate to advanced dementia towards the end of life. Whilst the general experience of caring by other carer groups, such as paid carers has been widely explored, accounts of home-based caregiving by family carers for moderate to advanced dementia were limited. Concepts which inform this study have been established including the meaning of a family carer as well as ‘home’ within the wider meaning of an institution. The establishment of these concepts is crucial to the scope of the study in understanding how the experience of caregiving for people with a moderate to advanced dementia is described.

## **Chapter 2: Exploring the literature on family carers' experiences of domestic home-based caring for people living with moderate to advanced dementia**

### **2.1 Introduction**

Current knowledge about the experience of family carers who provide home-based care for people living with moderate to advanced-stage dementia is based more on quantitative studies of people with dementia. This literature review was conducted to identify, synthesise, and evaluate the existing knowledge about their experiences. New approaches are explored to further understand how their own experience of caregiving is perceived especially towards the end of life of the care recipient.

Understanding the current literature promotes scholarship (Boyer, 2016). The review was based on the following question: '*How do family carers describe their experience of providing home-based care for people with moderate to advanced dementia?*' This provided the context and informed the methodology for evaluating existing knowledge on the experiences of the home-based caregivers.

### **2.2 The rationale for narrative synthesis review design**

A qualitative research method is useful for understanding people's experiences of a phenomenon. Historically, different methods have emerged for synthesising qualitative research (Dixon-Woods et al., 2005; Barbour & Barbour, 2003). A number of these methods, such as qualitative meta-analysis, thematic synthesis, content analysis and meta-narrative synthesis are all equally useful for the synthesis of evidence (Schick-Makaroff et al., 2016; Barnett-Page & Thomas, 2009). The review question required that the selected approach is fit for the purpose of aggregation and synthesis of evidence across multiple research methods. An approach for systematically describing, aggregating, analysing, and synthesising experiences of

home-based carers for people living with dementia across studies from multiple design methods was therefore warranted.

A technique such as meta-ethnography (as described by Noblit and Hare (1988)) was initially considered, given its systematic approach to searching across the different study types, settings and specific methodologies used (France et al., 2016). This technique is usually described as an inductive methodology for synthesising qualitative studies beyond mere aggregation of themes or summaries of identified literature (Britten et al., 2002). Meta-ethnography relies on the adaptation of new interpretations from the literature identified. However, the nature of this review suggests that a re-interpretation of findings from previously conducted research was unnecessary, given the paucity of evidence within the scope. Meta-ethnography also requires an in-depth understanding of the concept behind each study in order to re-interpret the findings or conclusions of all the studies identified. It was therefore considered inappropriate for exploring the recorded experiences of the family carers in this review.

This review focused on how the experience of home-based care for people with moderate to advanced dementia may be described by their caregivers. A textual narrative approach to the description of an experience was therefore considered. Similar to meta-ethnography, a textual narrative approach allows for transparency of the heterogeneity between studies (Lucas et al., 2007). This allows the fluidity in understanding the contexts and characteristics of each study without the distraction of the themes or concepts. Meta-ethnography, however, requires an in-depth understanding of the concept behind each study in order to re-interpret the findings or conclusions of all the studies identified. Hence, a textual narrative synthesis approach was selected as the review method given its appropriateness in ensuring that similarities and differences between multiple studies were systematically explored through synthesised words or texts (Popay et al., 2006).

A textual narrative synthesis involves grouping studies and making commentary comparisons between them, using their characteristics such as their data collection methods, authors, aims and their reported findings. However, the lack of transparency and clarity on how to conduct this type of synthesis is cited as its major weakness (Dixon-Woods et al., 2005; Mays et al., 2005). Following the guidance provided by Popay et al. (2006) offered assurance of clarity and transparency in this present review. Popay et al. (2006) consider that a theory may be used in giving the narrative inquiry a focus. Although this is also considered an optional strategy, some basic requirements are however regarded a necessity for adopting this design approach in a narrative synthesis (Popay et al., 2006). These are (a) identifying the review focus, (b) specifying the review question, (c) identifying studies to include, (d) data extraction and quality appraisal, (e) synthesising of the findings, and (f) reporting of findings. These steps were followed in the present review.

### **2.2.1 The review focus**

Accounts of caring for someone living with dementia are mostly rooted within negative experiences, such as associated burden (Lindeza et al., 2020; Bieber et al., 2019; Farina et al., 2017). Burden, in this respect, may be described as the impact of the difficulties associated with the dementia diagnosis which increases the level of uncertainty about the future for both the person with the disease and their family (Galvin & Sadowski, 2012; Phillips, 2011). It is recognised, however, that not all caregivers perceive their experiences as burdensome. Caregiving for some, is simply perceived in terms of related stress or coping with the difficulties experienced as part of the role. Evidence from primary studies identified in this present review suggests that caregiving continued, nonetheless. As such, understanding the reasons for caregiving continuation was imperative in this present review.

The meaning of caring may be viewed as a means by which a sense of personal responsibility and commitment is discharged towards a valued person, with a focus on their well-being (Swanson, 1991; 1993). The significance of a caregiver's involvement and the nature of care provided is also well documented. This was understood through a description of family carers as the family members, friends, relatives, or anyone who provides an unpaid but significant care for an ill person (Woodman et al., 2016). Based on these premises, an assumption may be made of an existence of a responsibility and commitment between the family carers and those cared for. Moreover, based on the focus of a description of the experiences of caregiving for those living with dementia towards the end of life, the description of the caregivers' participation in achieving well-being for those cared for is also important. The caregivers' actions or inaction may also be explored to ascertain their accounts of caregiving in understanding the possible determinants and justifications of their actions or inactions during caregiving, and their reasons for these.

The process of caring may be explored through the understanding of five processes suggested by Swanson (1991; 1993). In Swanson's view, maintaining belief in the capability of the person cared for in working through their challenges is a necessity in caring for an individual. Swanson also highlights the need for an act of trying to know or understand the meaning of an illness experience from the perspective of the person cared for. However, Swanson did not consider the possibility of understanding an illness experience without being with or spending time with the person cared for. According to Swanson (1993), the understanding of the meaning of an illness is only appropriate through the sharing of the feelings of its experience. In the processes described as 'doing for' and 'enabling', Swanson (1993) highlights as important, a carer's engagement in achieving for the person cared for, what they would have previously achieved without the assistance of others, as well as making it possible for the person cared for to help themselves within their present capability.

The processes of caring as described by Swanson's (1991; 1993) suggest that an act of caring requires an action being performed by the family carer. By clearly defining the data to be extracted and how this was to be conducted, this was useful as a focus for developing and answering the review question (McGaghie et al., 2001).

Furthermore, by adopting Swanson's view of caring in exploration of the caregiving experiences, the justification of the caregivers' actions during caregiving and their reasons was more likely to be understood. The determinants of these actions may also help towards better understanding of the reasons for the continuation of caring for someone with dementia.

The likelihood of the need for a variety of methods for exploring experiences of caregiving was considered in the adoption of the narrative synthesis approach for this review. According to Popay et al. (2006), a review focus will likely benefit from initial literature scoping during the systematic process, mainly for the avoidance of duplication. Indeed, Khan et al. (2003) suggest that forming an appropriate review question is a key step to identifying relevant studies to select, and which ones to exclude. The question coverage for this review was therefore extensive within the scope of interest (NICE, 2012). With the aim of exploring a broader account of caregivers' experience of home-based caregiving for people with dementia, ensuring the question is both appropriate and answerable was also crucial to the systematic exercise. A protocol was developed and published for this systematic process (James et al., 2020).

## **2.3 Methods**

### **2.3.1 Defining the review question and inclusion criteria**

Framing the review question must ensure the inclusion of the population of interest (Aslam & Emmanuel, 2010). A question, *'How do family carers describe their experience of providing home-based care for people with moderate to advanced*

*dementia?*' was therefore asked for the purpose of defining the scope and the inclusion criteria for this review (Table 2.1).

Table 2.1: Review inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
<b>Type of papers:</b> peer-reviewed empirical papers, qualitative papers including case studies and mixed-methods (both telephone and postal surveys are acceptable only if open-ended questions are asked)	<b>Type of papers:</b> Papers that are not primary research e.g. systematic reviews, meta-analysis
<b>Language of papers:</b> English	<b>Language of papers:</b> Papers in other languages
<b>Date:</b> Papers published from 1984 onwards	<b>Date:</b> Papers were written before 1984
<b>Population of focus:</b> unpaid family members or family carer	<b>Population of focus:</b> Population of focus relates to other groups of carers e.g. paid carers, professionals
<b>Age group:</b> 18 and above	<b>Age group:</b> Below 18
<b>Primary illness of interest:</b> moderate to advanced dementia as defined by the authors of identified studies in the abstract or full paper	<b>Primary illness of interest:</b> Other illnesses
<b>Setting:</b> domestic home setting, unpaid home-based care	<b>Setting:</b> Other formal care establishments where care provision is paid for
<b>Focus of papers:</b> current experiences or views or needs of family caregiver	<b>Focus of papers:</b> Focus on the views of others, or where death has already occurred

The use of a SPIDER (Sample, Phenomenon of interest, Design, Experience, Research type) methodology to define the inclusion and exclusion criteria was informed by the likelihood of achieving results of a more heterogeneous nature from the investigation of family carers' experience (Jahan et al., 2016; Methley et al., 2014; Cooke et al., 2012). As suggested by Popay et al. (2006), the key terms, dementia and family carers, and their variations were purposively selected for comprehensiveness of searches within qualitative and mixed methodologies (Table 2.2).

Table 2.2: SPIDER tool

S	<b>Sample</b> →	Family carers providing home-based care.
PI	<b>Phenomenon of Interest</b> →	Dementia (specifically at the moderate to advanced dementia stage).
D	<b>Design</b> →	Qualitative evidence collected from interviews, observations and surveys from studies adopting either qualitative or mixed method design.
E	<b>Experience</b> →	Subjective experiences, such as family carers' views, opinion, attitudes, and the reasons for this, with respect to home-based caregiving for people with moderate to advanced dementia.
R	<b>Research Type</b> →	Research adopting either qualitative or mixed methods (described in terms of exposure to specific elements of caregiving responsibilities leading to a noticeable change in behaviour or wellbeing of the sample (Schardt et al., 2007). Accounts of the duration of time spent caregiving and caregivers' feelings or emotions during care provision were also of interest.

### 2.3.2 Search strategy and process

Searches were conducted in MEDLINE Complete, CINAHL, EMBASE, PsycINFO, Web of Science, and Academic Search Complete. Websites and grey literature were also searched. For all searches, the terms and strategy used a broad range of terms and relevant keywords related to dementia, caregivers, and qualitative studies. These were checked by the two study supervisors (CW and CS), who were familiar with the domain of dementia and care provision. The search strategy was also tailored for use with each database, using Boolean operators, truncations, and Medical Subject Heading (MESH) as appropriate for each database (Table 2.3). A full electronic search using MEDLINE database is shown in Appendix 1.

Table 2.3: Search terms and strategy

Search terms and strategy
MH "Dementia+" OR TX dement* OR TX alzheimer * OR TX "lew* bod*" OR TX FTLD OR FTD OR frontotemporal
<b>AND</b> TX carer* OR TX caregiv* OR TX care-giver OR TX spouse-caregiver*
<b>AND</b> MH "Qualitative Research+" OR MH "qualitative studies" OR MH "Focus Groups" OR MH "exploratory+" OR MH "qualitative interview+" OR MH "ethnography+" OR MH "ethnographic research" OR MH "content analysis" OR MH "Grounded theory"

The decision to include all papers published from 1984 onwards was based on the reported increase in diagnosis and people caring informally (Lewis et al., 2014). Supplementary searches of reference list from identified studies were also conducted. The list of studies returned from searches was imported into Endnote, an online reference management software (Lorenzetti & Ghali, 2013), to remove duplicates and ensure the validity and reliability of the review process' (Kwon et al., 2015) (See table 2.3).

Many papers were found where the population of interest was either missing or incorrectly reported. In some instances, papers were also inaccurate in relation to the description of their design, focus and disease stage. This made exclusion difficult through their titles and abstract. The screening stage was therefore problematic as 2248 full-text articles were reviewed so that eligibility decisions could be made. Seventeen papers were included in the narrative synthesis, and others were excluded (Fig 2.1).

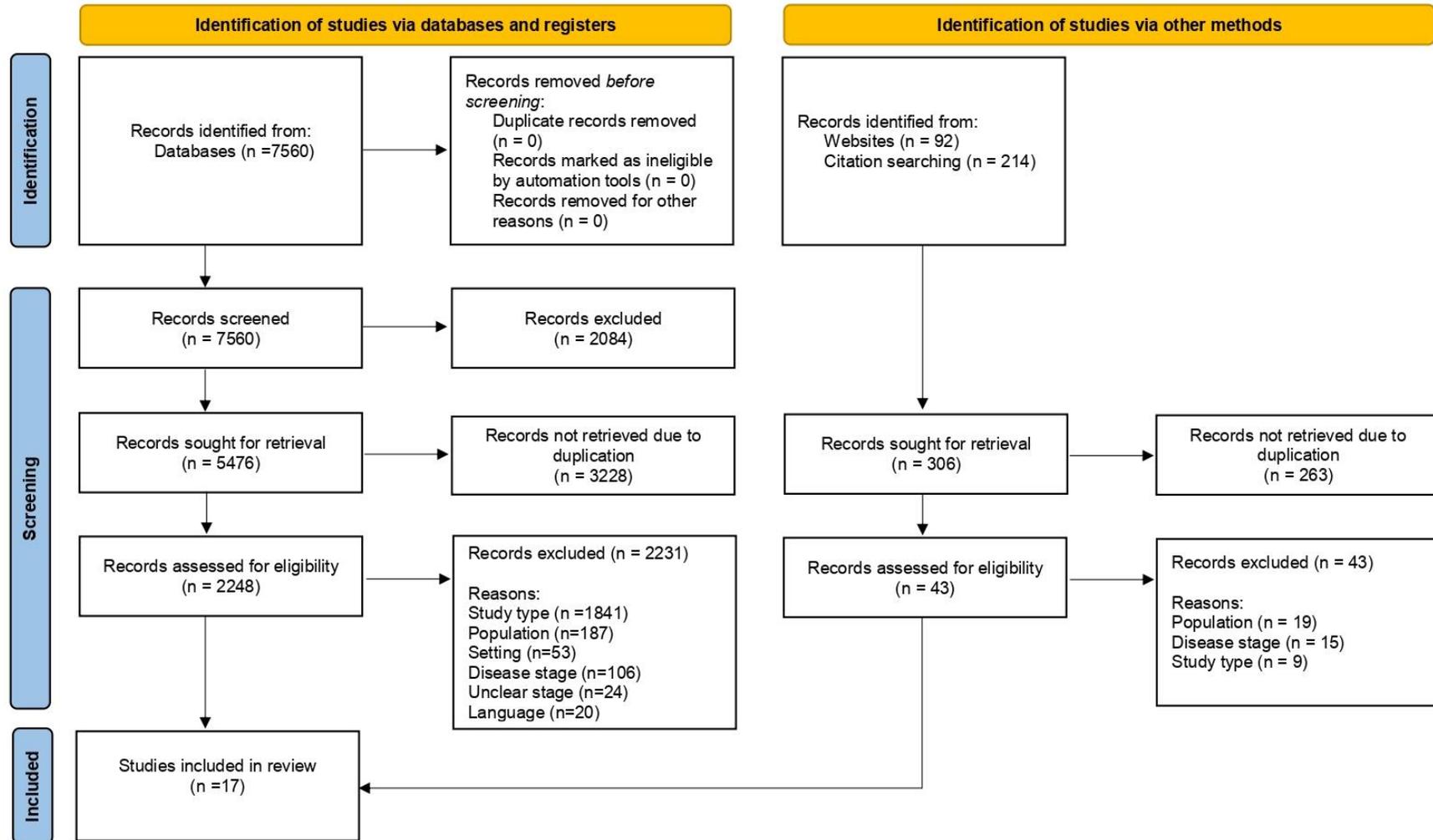


Fig 2.1: Sources of studies included (PRISMA diagram adapted from Page et al., 2020).

### **2.3.3 Data extraction**

The decision on which data to extract and its quality have implications for the conclusions of aggregated evidence (Popay et al., 2006). In terms of evidence strength, and weight or robustness, specific methods on how this may be conducted were not prescribed in the literature. The extraction of qualitative data was however sufficient as suggested by Popay et al. (2006). Key data such as author's name, publication origin and year, setting, population and sample size, aim and objectives, data collection method and main findings, which show the caregivers' actions were extracted from each paper included in this review. In some cases, the determinants of these actions were also reported in the findings. Systematic assessment of papers' quality and relevance was also used in data extraction and appraising their reported findings (Al-Jundi & Sakka, 2017; Burls, 2016; Popay et al., 2006;).

### **2.3.4 Quality and bias assessment**

An absolute benchmark for judging a good qualitative research paper is difficult. According to Popay et al. (1998), presented evidence must be supported with clearly defined criteria. A non-discriminatory tool developed by Hawker et al. (2002) and adapted by Lorenc et al. (2014) was used in assessing the quality of included papers, based on the adaptability of its structure to a variety of methodologically distinctive designs. This tool uses a checklist of nine categories for assessing the quality of selected papers. In the review, the first seven categories on the checklist show the trustworthiness of the paper being assessed. The last two categories represent individual paper's relevance. The score attached to each paper represents its weight and demonstrates its relevance and appropriateness in comparison to others also included (Popay et al., 2006).

A maximum of 36 points was allocated as a range for categorising and determining the papers' quality according to their methodological rigour (Hawker et al., 2002).

Each paper was assigned a rating of 'good' (4 points), 'fair' (3 points), 'poor' (2 points) or 'very poor' (1 point) in the nine categories. Lorenc et al. (2014) further suggest a modified approach for ratings representation which ensures a clearer understanding of how gradings are represented. With this approach, a high-quality paper may be graded 'A', with a score between 30 and 36 points. A medium-quality paper may be graded 'B', with a score between 24 and 29. A paper with a score between 9 and 24 would however be considered a low-quality paper and graded 'C'. Ratings were therefore allocated accordingly in the review to show methodological rigour and quality of included papers. To further reduce any ambiguity in ratings, grading for a low-quality paper was modified to a range between 9 and 23, which did not impact the grading allocation as originally suggested by Hawker et al. (2002). The two study supervisors, CW and CS, reviewed the studies included in the review and checked the result of the appraisal process to ensure the appropriateness of the tool selected as well as the overall process of quality assessment (Table 2.4).

Table 2.4: Result of the quality assessment of included studies

Author	Abstract/title	Introduction /aims	Data collection	Sampling	Analysis	Ethics/ Bias	Results/ Findings	Generalisability	Implication	Total	Grade
<b>Adams &amp; Sanders (2004)</b>	3	4	4	4	4	2	3	2	3	29	B
<b>Brunton et al. (2008)</b>	3	4	4	4	4	4	4	2	4	34	A
<b>Chan et al. (2010)</b>	4	4	4	4	4	4	4	4	4	36	A
<b>Colling (2004)</b>	3	4	4	4	4	4	4	4	4	35	A
<b>de La Cuesta-Benjumea (2011)</b>	4	4	4	4	4	4	4	4	4	36	A
<b>De Silva and Curzio (2009)</b>	4	4	3	1	3	4	4	2	4	29	B
<b>Hirschman et al. (2006)</b>	3	4	4	4	4	4	4	4	4	35	A
<b>Idura et al. (2018)</b>	4	3	4	4	4	4	4	4	4	35	A
<b>Karger (2018)</b>	4	4	4	4	4	1	4	4	4	32	A
<b>Lamahewa et al. (2018)</b>	4	4	4	2	4	4	4	2	4	32	A
<b>Lethin et al. (2016)</b>	4	4	4	4	4	4	4	4	4	36	A
<b>Lindauer et al. (2016)</b>	4	4	4	4	4	4	4	4	4	36	A
<b>Moore et al. (2017)</b>	4	4	4	4	4	4	4	4	4	36	A
<b>Robinson et al. (2010)</b>	3	4	4	4	4	4	4	4	4	35	A
<b>Smith et al. (2001)</b>	3	4	4	4	4	4	4	4	4	35	A
<b>Tretteteig et al. (2017)</b>	4	4	4	3	4	4	4	4	4	35	A
<b>Wladkowski (2016)</b>	3	4	4	4	4	4	4	4	4	35	A

All the papers included (n=17) were published in peer-reviewed journals, but only 15 papers were appraised as high-quality in this review. The remaining two papers by Adams and Sanders (2004) and De Silva and Curzio (2009), were considered to be of a medium quality. The findings of these two papers were in accordance with the findings from other included papers. Their value to the review was therefore

recognised along with other papers for which higher scores were recorded. Their inclusion was based on their contribution to answering the specified review question (Popay et al., 1998). Inter-rater reliability was not considered a necessary part of the quality appraisal given the defined inclusion criteria for selected papers (McDonald et al., 2019).

## **2.4 Review findings**

The review result show that whilst eight studies presented data from those only caring for people with advanced dementia, nine included data from those caring for people with both moderate dementia, described by some participants as the middle stage, and advanced dementia, which was regarded as the severe or late-stage dementia. Extrapolation from experiences at both stages of dementia was therefore necessary. For instance, the study by Tretteteig et al. (2017) was conducted as part of a larger study which took place over 24 months. Although the evidence showed that participants' consent was sought before taking part in a study conducted by Tretteteig et al. in 2017, the duration between both studies was not discussed, thereby making it unclear how participants' responses may have been impacted.

A diverse mix of unpaid family caregivers, identified as spouses, adult children, in-laws and other relatives participated in 15 of the 17 studies reviewed (Adams & Sanders, 2004; Colling, 2004; Hirschman et al., 2006; Lindauer et al., 2016; Smith et al., 2001; Robinson et al., 2010; Tretteteig et al., 2017; Lethin et al., 2016; de La Cuesta-Benjumea, 2011; Colling, 2004; De Silva & Curzio, 2009; Lamahewa et al., 2018; Moore et al., 2017; Wladkowski, 2016; Idura et al., 2018). The remaining studies also included the views of professionals (Karger, 2018; Lamahewa et al., 2018). Only the accounts of family caregivers were included from these papers in this present review. To maintain the purpose of this present review, only qualitative data were extrapolated. Also, while the review was not focused on establishing a comparison of experiences between genders, it is noteworthy that only two studies

were dedicated solely to accounts from female caregivers (De Silva & Curzio, 2009; de La Cuesta-Benjumea, 2011).

The review findings are presented in three stages. In the first stage, systematically extracted data were tabulated to display the similarities and differences between the findings of each selected paper (Popay et al., 2006). The extracted data, according to Popay et al. (2006), are those that may guide the interpretation of results between different settings or groups. As such, the data extracted included the author, setting, population, aims/objectives, research design, data collection method and findings (Table 2.5).

Table 2.5: Characteristics of included studies

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
Adams and Sanders (2004)  [USA]	Homebased	<b>Sample:</b> Informal caregivers (n=74)  <b>Sampling method:</b> Convenience sampling  <b>Stage:</b> Moderate to advanced	To explore self-reported losses, grief reactions and depressive symptoms among a sample of caregivers of persons with Alzheimer's disease or other progressive dementia	<b>Type:</b> Mixed method  <b>Design:</b> Cross-sectional	<b>Data collection:</b> Open-ended postal survey  <b>Analysis:</b> Cross-sectional analysis	a) Caregivers for individuals within the late stage of dementia reported significantly more symptoms of grief and depression than those in the early or middle stages; b) The late-stage experience mostly resembled bereavement.
Brunton et al. (2008)  [New Zealand]	Homebased	<b>Sample:</b> Family caregivers  1 <sup>st</sup> stage: (n=5)  2 <sup>nd</sup> stage: (n=64)  <b>Sampling method:</b> Purposive, non-probability  <b>Stage:</b> Stage 2 to Stage 5	To explore the lived experience and perceptions of a sample of caregivers who are providing informal care 24hr per day, seven days per week for those with Alzheimer's disease in New Zealand.	<b>Type:</b> Mixed method  <b>Design:</b> Exploratory	<b>Data collection:</b> Semi-structured interview and questionnaires (using open-ended questions)  <b>Analysis:</b> Thematic analysis	a) High cost of caring is reported as a form of negative impact on caregiver's physical and psychological health; b) Difficulty in asking for help from family; c) Caregivers were concerned about finances and fears for the future; d) Caregivers reported also reported the need to be free, need for a time out, need for a role change and a need to be someone else.

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
Chan et al. (2010)  [Hong Kong]	Community homebased	<b>Sample:</b> Informal caregivers (n=27)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Moderate to advanced	To report the lived experience of caregivers of persons with dementia in Hong Kong, and to explore their service needs.	<b>Type:</b> Qualitative  <b>Design:</b> Focus group	<b>Data collection:</b> Focus group interviews  <b>Analysis:</b> Colaizzi's phenomenological analysis	a) Caregivers were confused about the nature of their care recipients' disease; b) Negative report of caregiving in terms of grief, sadness, guilt, anger and fear; c) The needs of caregivers changed in line with the care recipient's disease progression; d) Caregiving responsibilities increased as the illness progressed; (e) Difficulty in coping with increasing care recipient's behavioural changes; (f) Increased caregiving responsibilities conflicted with other social roles, such as employment and other social activities; g) Burden reduces in the advanced stage of dementia as role acceptance increases.
Colling (2004)  [USA]	Homebased	<b>Sample:</b> Family caregivers   Moderate (n=16), Advanced (n=19)  <b>Sampling method:</b> Purposive	To describe how the experience of passivity was for the caregiver and the person with Alzheimer's disease.	<b>Type:</b> Qualitative  <b>Design:</b> Phenomenology	<b>Data collection:</b> Semi-structured interviews  <b>Analysis:</b> content analysis (using Colaizzi's thematic extraction)	a) Passivity increased over time as the disease worsened;b) Experience of emotions such as fatigue, sadness, tears, frustration and a sense of helplessness; c) Caregivers of moderately impaired persons found it stressful to cope with lifestyle changes associated with caregiving; d) Caregivers of severely impaired persons expressed the most sadness associated with experiencing the process of cognition deterioration in their loved ones; e) at the moderate stage found it stressful to cope

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
		<b>Stage:</b> Moderate to advanced				with lifestyle changes associated with caregiving, a sense of helplessness and frustration at watching behavioural changes in the care recipient
de La Cuesta-Benjumea (2011)  [Spain]	Homebased	<b>Sample:</b> Female family caregivers (n=23)  <b>Sampling method:</b> Purposeful and theoretical  <b>Stage:</b> Advanced	To explore strategies women caregivers of relatives with advanced dementia use to rest from caregiving	<b>Type:</b> Qualitative  <b>Design:</b> Grounded theory	<b>Data collection:</b> Semi-structured interviews  <b>Analysis:</b> Grounded theory (constant comparison analysis)	a) Taking leave from the life of caregiving is used by the caregivers as a strategy to rest from their caregiver selves; b) Caregivers did not perceive respite to mean resting or being idle. For them, respite is considered as doing something different, and by thinking and relating to others in different ways than those linked to caregiving.
De Silva and Curzio (2009)  [UK]	Homebased	<b>Sample:</b> Female family caregivers (n=10)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Advanced	To explore the life experiences of family carers in the transition from home into long-term care	<b>Type:</b> Qualitative  <b>Design:</b> Phenomenology	<b>Data collection:</b> One-to-one interviews  <b>Analysis:</b> Thematic analysis	a) Deterioration of behaviour is a major reason for care recipient transitioning into long-term care; b) Although alternatives to long-term care were offered before placement, several did not receive much support and felt isolated; c) Spousal caregivers reported great sadness in placing their loved one; d) Difficulty in finding the right place; e) Severity of dementia and the complex health needs of a loved one left caregivers no other choice but long-term care; f) Experience of guilt or emotional distress during the transition.

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
Hirschman et al. (2006)  [USA]	Homebased	<b>Sample:</b> Family caregivers (n=30)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Advanced	To identify what standard of decision making a family member uses when making medical decisions for their relative with advanced dementia	<b>Type:</b> Qualitative  <b>Design:</b> Qualitative	<b>Data collection:</b> Semi-structured interviews  <b>Analysis:</b> Thematic analysis	a) Making medical decisions is difficult for caregivers, and there is no guidance as to how this is done; b) Either substituted judgement (what the care recipient would have wanted) (n=2) or best interest (opinion of the caregiver for deciding what is best for the care recipient) (n=17). In some cases, decisions are made by combining both as care recipients (n=11) often fail to have discussions about end of life with their family; c) Barriers highlighted include: avoiding the topic, waiting too long and denial of dementia by the care recipient and sometimes the caregivers themselves.
Idura et al. (2018)  [Malaysia]	Homebased	<b>Sample:</b> Family caregivers (n=12)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Moderate to advanced	To describe the experience of Malaysian family caregivers' experiences in providing care to their family members with moderate to advanced dementia	<b>Type:</b> Qualitative  <b>Design:</b> Qualitative	<b>Data collection:</b> In-depth semi-structured interviews  <b>Analysis:</b> Thematic analysis	a) Increased severity did not increase caregivers' burden due to acceptance of the caregiving role; b) Caregivers' grief increases with severity; c) Burden increases at the earlier stages; d) Caregivers felt it was their responsibility to provide care; e) Family support as a possible reason for a reduced burden; f) Family support is a positive experience in helping to improve relationships among family members; g) Family support was not always available.

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
Karger (2018) [Germany]	Homebased	<b>Sample:</b> Relatives (n=20)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Advanced	To gain insight into families and professionals' understanding of the emotional experience in patients with advanced Alzheimer's disease	<b>Type:</b> Qualitative  <b>Design:</b> Focus group	<b>Data collection:</b> Group interviews  <b>Analysis:</b> Qualitative content analysis and framework analysis	a) Relatives perceived emotionality as one of the essential characteristics retained despite the illness; b) loss of emotional experience increased with loss of cognitive capacity and verbal expression; c) shared memories faded with illness progression; d) memories forgotten no longer held any emotional significance for the care recipient; e) Perceived discontinuity of patient's emotional responses contrary to relatives' expectations creates ambiguity; f) Patients' behaviour which is different to expectations is a distressing experience for the relatives.
Lamahewa et al. (2018) [UK]	Homebased	<b>Sample:</b> Family caregivers  Current (n=6)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Advanced	To explore the difficulties in decision making for family carers and practitioners at the end of life	<b>Type:</b> Qualitative  <b>Design:</b> Focus group	<b>Data collection:</b> Semi-structured interviews  <b>Analysis:</b> Thematic analysis	Making decisions is particularly difficult at the end of life and associated with caregivers' unpreparedness
Lethin et al. (2016) [Sweden]	Homebased (also nursing home)	<b>Sample:</b> Family caregivers (n=23)	To investigate family caregivers' experiences of formal care when	<b>Type:</b> Qualitative	<b>Data collection:</b> Focus group interviews	a) Caregivers' feeling of inadequacy and striving to remain in control, while avoiding being a burden and struggling to avoid dependence on

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
		<p><b>Sampling method:</b> Strategic</p> <p><b>Stage:</b> <i>Advanced</i> (also includes accounts of early stages)</p>	caring for a person with dementia through the stages of the disease	<p><b>Design:</b> Focus group</p>	<p><b>Analysis:</b> Content analysis</p>	formal care; b) Worry about the future and the capacity to continue caregiving; c) Feelings of being alone and isolated because formal care was not as supportive as expected; d) Increasingly isolated when friends and family no longer came to visit
Lindauer et al. (2016)  [USA]	Homebased	<p><b>Sample:</b> Family caregivers (n=11)</p> <p><b>Sampling method:</b> Purposive</p> <p><b>Stage:</b> Moderate to advanced</p>	To explore the meaning AA family caregivers ascribed to dementia-related changes in care recipients	<p><b>Type:</b> Qualitative</p> <p><b>Design:</b> Interpretative Phenomenological Approach</p>	<p><b>Data collection:</b> In-depth interviews</p> <p><b>Analysis:</b> Interpretative Phenomenological Approach (IPA)</p>	a) Dementia-related changes meant that caregivers had to hang on to the care recipient for as long as possible; b) Caregiver's recognition that the valued care recipients were changed but still here and worthy of respect and compassion; c) Valued care recipients were changed, but still here, was regarded as a paradox; d) Family values, shaped by historical oppression, influenced caregiving meanings; e) Caregivers did not consider they were grieving, as their care recipient was <i>still here</i> .
Moore et al. (2017)  [UK]	Homebased  (part of a larger study including care-home	<p><b>Sample:</b> Family carers (n=6)</p> <p><b>Sampling method:</b> Stratified</p>	To understand the experiences of carers during advanced dementia and to explore the links between	<p><b>Type:</b> Mixed methods</p> <p><b>Design:</b></p>	<p><b>Data collection:</b> In-depth interviews</p> <p><b>Analysis:</b> Thematic analysis</p>	a) Difficulty in understanding dementia progression and being involved during advanced stages; b) Placing care recipient in a care home is perceived as a loss of control, and a need for heightened vigilance; c)

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
	as the setting)	<b>Stage:</b> Advanced	mental health and experiences of end of life care.	Longitudinal cohort study		The unpredictability of dementia led to challenges in preparing for the end of life; d) Grief is a staged-process and high levels of guilt and grief into bereavement is linked to the inability to effect change in care provision
Robinson et al. (2010) <b>[Canada]</b>	Homebased	<b>Sample:</b> Family caregivers (n=29)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Advanced	To understand how family caregivers of institutionalised relatives with dementia perceived and experienced relocation of their relative to a more home-like setting	<b>Type:</b> Mixed methods  <b>Design:</b> Focus group	<b>Data collection:</b> Focus group and individual interviews  <b>Analysis:</b> Thematic analysis	a) Caregivers often exhaust their physical, cognitive, emotional resources before agreeing to have their family member placed in care; b) The family caregiver's relational connection to the member with dementia remained strong and generated suffering when placement occurred that persisted over time and, for some, increased. This suffering took the form of grieving the losses arising from placement, guilt for being unable to prevent placement, second-guessing themselves with regards to the necessity of placement, and concern over the circumstances of the care.
Smith et al. (2001) <b>[USA]</b>	Homebased	<b>Sample:</b> Primary caregivers (family) (n=45)  <b>Sampling method:</b> Purposive	To explore caregivers' narratives of their experience and needs, and how the disease and their interaction with	<b>Type:</b> Qualitative  <b>Design:</b> Ethnography	<b>Data collection:</b> Semi-structured intensive interviews	a) Family caregivers had financial worries, with those identified as spouses expressing higher levels of anxiety; b) Some caregivers' needs seemed more dependent upon unfulfilled expectations from family, support systems, or practitioners; c) Disappointment at the level of care,

Author/date/ Country	Setting	Population/ sample size/ sampling method/ illness stage	Aim/objectives	Research type/ research design	Data collection & analysis	Findings
		<b>Stage:</b> Mild to advanced	multiple practitioners have impacted their lives		<b>Analysis:</b> Thematic analysis	emotional support, or love expressed by family members
Tretteteig et al. (2017) <b>[Norway]</b>	Homebased	<b>Sample:</b> Family caregivers (n=5)  <b>Sampling method:</b> Purposive  <b>Stage:</b> Moderate to advanced	To gain knowledge about family caregivers' experiences of meaning in their caring role	<b>Type:</b> Qualitative  <b>Design:</b> Narrative (using Riessman's method)	<b>Data collection:</b> In-depth semi-structured interviews  <b>Analysis:</b> Narrative analysis method using a case study approach	a) Caregivers' roles and coping strategies were related to their relational ties; b) Difficulty in accepting their care recipient had changed; c) Caregivers had to make decisions whether to enhance, maintain or let go of emotional ties to find a good balance between meeting own needs and care recipient's needs; d) Letting go is almost impossible due to having a shared history with care recipient
Wladkowski (2016) <b>[UK]</b>	Homebased	<b>Sample:</b> Family caregivers (n=24)  <b>Sampling method:</b> <i>Purposive</i>  <b>Stage:</b> <i>Advanced</i>	To explore the grief experience in end-of-life care by caregivers	<b>Type:</b> Qualitative  <b>Design:</b> Qualitative	<b>Data collection:</b> Semi-structured interviews  <b>Analysis:</b> Thematic analysis	a) Unpreparedness for a change in terminal prognosis and uncertainty about being able to resume caregiving for their loved one following a live discharge; b) Emotional conflict in understanding disease progression following a live discharge, which also caused a struggle in understanding care recipient's terminal prognosis as being temporary; c) A level of ambiguity in the caregivers' grief process as caregivers become unsure of how or when to grieve.

According to Popay et al. (2006), using the researcher's own themes when presenting a review of the findings ensures a continuity of concepts across included studies. In this second stage of the findings' presentation, papers were grouped according to the disease stage, country, authors and population, and the common focus identified in the literature. A textual narrative synthesis of the common focus between included studies was also presented, which shows the inter-relationship between the different studies in terms of their commonality on how caregiving experiences differ at both the moderate and advanced stages of dementia (Table 2.6).

Table 2.6: Textual narrative synthesis exploring relationships between studies

Stage	Country	Authors and combined population across all locations and participants type (Family caregivers: including spouses, adult children, in-laws and other relatives)	Common focus between studies
Moderate to advanced stage	USA	Adams and Sanders (2004) [moderate (n=41), advanced (n=33)]  Colling (2004) [moderate (n=16), advanced (n=19)]  Smith et al. (2001) [moderate (n=21), advanced (n=11)]  Lindauer et al. (2016) [Total participants (n= 11), specific stage breakdown was not given in paper]	Determinants of how the experience of loss, burden and grief reactions symptoms are expressed at the moderate stage and how caregivers make sense of dementia-related changes
	Hong Kong	Chan et al. (2010); [Total participants (n= 27), stage breakdown was not given in paper]	
	Norway	Tretteteig et al. (2017) [moderate (n=2), advanced (n=2)]	Determinants of factors that influence the caregivers' perception of their own needs and motivation in the role of caring for their family members
	Malaysia	Idura et al. (2018) [moderate (n=6), advanced (n=6)]	
Advanced stage	Hong Kong	Chan et al., (2010) [Total participants (n= 27), specific	Determinants of how the experience of loss, burden and grief

Stage	Country	Authors and combined population across all locations and participants type (Family caregivers: including spouses, adult children, in-laws and other relatives)	Common focus between studies
		<i>stage breakdown was not given in paper]</i>	reactions symptoms are expressed at the advanced or severe stage and how caregivers make medical decisions and make sense of dementia-related changes
	USA	Adams and Sanders, (2004) [advanced (n=33)] Colling (2004) [advanced (n=19)] Smith et al., (2011) [advanced (n=11)] Hirschman et al. (2006) [advanced (n=30)] Lindauer et al. (2016) [Total participants (n= 11), specific stage breakdown was not given in paper]	
	UK	De Silva and Curzio, (2010) [advanced (n=10)] Lamahewa et al., (2018) [advanced (n=10)] Moore et al., (2017) [advanced (n=6)] Wladkowski (2016) [advanced (n=24)]	
	Germany	Karger (2018) [advanced (n= 20)]	Factors that influence caregivers' emotional response to the grieving process/impact on caregivers' grieving process and influence decision-making strategies at the advanced stage/end of life
	Sweden	Lethin et al. (2016) [advanced (n= 23)]	Factors that influence how caregivers' view formal care for their relatives during advanced dementia
	Canada	Robinson et al., (2010) [advanced (n= 29)]	
	New Zealand	Brunton et al. (2008) [Total participants (n= 5), specific stage breakdown was not given in paper]	Determinants of the need for rest and coping strategies in caregivers' role at the advanced stage

Stage	Country	Authors and combined population across all locations and participants type (Family caregivers: including spouses, adult children, in-laws and other relatives)	Common focus between studies
	Spain	de La Cuesta-Benjumea, (2011) [advanced (n= 23)]	

A preliminary synthesis is presented in the third stage. This is a crucial element in describing patterns across the reviewed papers (Popay et al., 2006). Thus, a synthesis of the findings and methods was grouped and presented as a tabulation using headings: population, dementia stage, location and design for the display and comparison of included studies. The preliminary synthesis is also an initial stage to the interpretation of the presented results (Popay et al., 2006). As a test for the robustness of the synthesis result, an interrogation of this initial synthesis is required to understand the reasons for the findings presented by each study included (Popay et al., 2006). Hence, a further tabulated textual comparison of the studies included was also undertaken (Table 2.7).

Table 2.7: Preliminary synthesis of studies

Design	
Cross-sectional	Adams and Sanders (2004)
Longitudinal cohort	Moore et al. (2017)
Focus group	Chan et al. (2010); Karger (2018); Lamahewa et al. (2018); Lethin et al. (2016); Robinson et al. (2010)
Phenomenology (including Interpretative Phenomenological Approach)	Colling (2004); De Silva and Curzio (2009); Lindauer et al. (2016)
Qualitative	Hirschman et al. (2006); Idura et al. (2018); Wladkowski (2016)
Grounded theory	de La Cuesta-Benjumea (2011)
Exploratory	Brunton et al. (2008)
Ethnography	Smith et al. (2011)
Narrative (Case study)	Tretteteig et al. (2017)
Population	
Family caregivers (generic category including spouses, adult children, in-laws)	Adams and Sanders (2004); Brunton et al. (2008); Chan et al. (2010); Colling (2004); De Silva and

and other relatives)	Curzio (2009); Hirschman et al. (2006); Idura et al. (2018); Karger (2018); Lamahewa et al. (2018); Lethin et al. (2016); Lindauer et al. (2016); Moore et al. (2017); Robinson et al. (2010); Tretteteig et al. (2017); Wladkowski (2016)
Family caregiver (spouses only)	de La Cuesta-Benjumea (2011)
<b>Dementia stage</b>	
Advanced or severe	Brunton et al. (2008); de La Cuesta-Benjumea (2011); De Silva and Curzio (2009); Hirschman et al. (2006); Karger (2018); Lamahewa et al. (2018); Lethin et al. (2016); Moore et al. (2017); Robinson et al. (2010); Smith et al. (2001); Wladkowski (2016)
Moderate to advanced or severe (Combined accounts)	Adams and Sanders (2004); Chan et al. (2010); Colling (2004); Idura et al. (2018); Lindauer et al. (2016); Tretteteig et al. (2017)
<b>Location</b>	
United Kingdom (UK)	De Silva and Curzio (2009); Lamahewa et al. (2018); Moore et al. (2017); Wladkowski (2016)
United States of America (USA)	Adams and Sanders (2004); Colling (2004); Hirschman et al. (2006); Lindauer et al. (2016); Smith et al. (2001)
Norway	Tretteteig et al. (2017)
Sweden	Lethin et al. (2016)
Hong Kong	Chan et al. (2010)
New Zealand	Brunton et al. (2008)
Spain	de La Cuesta-Benjumea (2011)
Germany	Karger (2018)
Canada	Robinson et al. (2010)
Malaysia	Idura et al. (2018)

## 2.5 Textual narrative synthesis of findings

The purpose of this review was to understand how caregivers described their experience of home-based care for people with moderate to advanced dementia. All the papers included contributed to different aspects of experiences within the defined criteria for inclusion. The textual narrative synthesis shows caregivers' differentiated accounts of their burden, loss, grief, how they coped with challenges and continued with care provision within the stages of dementia explored. In congruence with Popay et al. (2006), the navigation of the textual narrative is sequential. Hence, the

presentation of the findings starts with the caregivers' account of their caregiving-associated burden, followed by accounts of their loss, and the grief experienced.

The textual narrative synthesis ends with descriptions of how caregivers deal with challenges that arise during caregiving and their motivation for carrying on. These experiences are discussed individually under their respective headings and a comparison of how each of these is experienced at the moderate and advanced stages is also made. Participants' direct verbatim quotes are *italicised* in double quotation marks. These are however separated from the main discussions, and presented in Appendix 2 under the headings: 'Experiences', 'Quotes/Comments' and 'Paper'. The reviewer's emphasis on terminologies developed from the concepts identified in the literature was also *italicised* in the discussion of the findings which show the participants' descriptions of their burden, loss, grief and how they deal with challenges towards the end of life while caring for someone living with dementia within the moderate and the advanced stages.

### **2.5.1 Burden: experiences at moderate and advanced stages**

Caregivers in the moderate stage experienced increased caregiving responsibilities due to increased care recipient's needs (Idura et al., 2018; Chan et al., 2010; Adams & Sanders, 2004). Extended time was spent caregiving as a result, which led to a clash with other social roles, and a difficulty in meeting caregiver's own needs (Idura et al., 2018; Chan et al., 2010). In the case of spousal caregivers, extended time spent on caregiving was also highlighted (Idura et al., 2018; Chan et al., 2010; Adams & Sanders, 2004). Whilst the extended time caregiving was considered a necessity in some cases as highlighted by Adams and Sanders (2004), the reason for this was not given. Swall et al. (2019) and Hellström et al. (2005) suggested, however, that this may be attributable to their couplehood.

Increased caregiving responsibilities caused caregivers' increased burden at the moderate stage of dementia (Adams & Sanders, 2004). Caregivers' difficulty in meeting their own needs also intensified over time (Chan et al., 2010). This finding represented a high cost of caring with possible risk to caregivers' mental and physical health (Idura et al., 2018; Brunton et al., 2008; Adams & Sanders, 2004). Furthermore, contrary to the report of an increase in caregiving being the only association to caregivers' increased burden, evidence also showed that caregivers' increased burden was linked with progressive decline and changes in the care recipient's behaviour (Idura et al., 2018; Karger, 2018; Lindauer et al., 2016; Chan et al., 2010).

The collective account at the advanced stage further associated caregivers' burden with care recipient's behavioural changes, which existed as part of progressive decline in dementia (Colling 2004). Passivity, a distinctive change in care recipient's behaviour, which also affect functionality in thinking, movement, and interactions with others was cited as an example (Colling, 2004). However, the severity of this change did not increase caregivers' burden (Idura et al., 2018; Chan et al., 2010). Passivity also changed care recipient's emotional responses and causes caregivers' difficulty in accepting changes in the care recipient (Karger, 2018). Overall, as care recipient's passivity increased, caregivers' helplessness, sadness, and frustration at the inability to help also increased (Colling, 2004).

Passivity was however not only distinctive at the advanced stage. Common symptoms of increased agitation, aggression, and withdrawal were also reported at the moderate stage (Lindauer et al., 2016; Chan et al., 2010; Colling, 2004). As care recipients became more passive and required help with functional activities such as personal care, the demand for their caregivers' attention also increased (Colling, 2004). This also caused caregivers' burden to increase in line with care recipients' increasing passivity at this stage of the disease.

Caregivers also found it difficult to accept the process of their care recipients' decline and expressed the most sadness at the advanced stage (Colling, 2004). Despite this, they accepted their role better, as they were adjusted to their new lifestyle (Chan et al., 2010; Colling, 2004). In comparison, less burden was reported by caregivers at the moderate stage (Colling, 2004), which was attributed to their reliance on external resources such as extended family support (Idura et al., 2018; Chan et al., 2010; Brunton et al., 2008). While the availability of external support was commonly perceived as being able to reduce burden by caregivers for care recipients at both stages of dementia (Idura et al., 2018; Chan et al., 2010), evidence of the consistency in burden reduction at either stage was not discussed in the reviewed literature.

While some caregivers were assisted by their extended family (Brunton et al., 2008; Smith et al., 2001), others experienced a difficulty in asking for support (Chan et al., 2010; Brunton et al., 2008; Smith et al., 2001). Also, some had to "*apply pressure*" to receive any assistance at all (Brunton et al., 2008), and disappointment was sometimes experienced by these caregivers at the level of assistance offered (Smith et al., 2001). Though some positive experiences were reported, such as the report of an improvement to inter-relationships (Idura et al., 2018; Chan et al., 2010), however, tension within the family was also a possibility (Chan et al., 2010). This also supports the finding that reduction of caregivers' burden through extended family support at both stages of dementia was not true in all cases.

Poor understanding of caregivers' needs (Idura et al., 2018; Chan et al., 2010), was commonly evidenced as one of the factors for inadequate familial assistance at both stages (Chan et al., 2010; Brunton et al., 2008). Other reasons include living away from the care recipient (Chan et al., 2010; Brunton et al., 2008), and familial indifference (Chan et al., 2010; Brunton et al., 2008). Receiving assistance from the family was therefore not always available. Moreover, it was possible for family

expectations to attach a sense of duty to caregiving (Idura et al., 2018; Tretteteig et al., 2017; Chan et al., 2010). As such, caregiving therefore became an obligation at both stages (Idura et al., 2018; Chan et al., 2010).

### **2.5.2 Loss: experiences at moderate and advanced stages**

Caregivers' loss was explored from two perspectives. The first, mostly descriptive of caregivers' narrative at the moderate stage, was related to caregivers' personal changes. This was described in relation to caregiver's time, freedom, independence and being able to socialise (Idura et al., 2018; Chan et al., 2010; Brunton et al., 2008; Adams & Sanders, 2004). These lifestyle changes were stressful (Colling et al., 2004), and attributable to their increased caregiving responsibilities (Chan et al., 2010; Adams & Sanders, 2004; Colling, 2004). It was further reported by those who identified themselves as spouses, that this type of loss was highest, especially in cases where caregiving ceases to be provided at home at the advanced stage of the disease (Adams & Sanders, 2004). Their loss was also accompanied by guilt (Adams & Sanders, 2004).

The second perspective was associated with care recipient's changes, mostly at the advanced stage. This was described as care recipient's altered behaviour (Colling 2004), and difference over time (Adams & Sanders, 2004; Colling, 2004). For this type of loss, care recipients were described in relation to who they once were (Lindauer et al., 2016; Adams & Sanders, 2004), in terms of their personality (Tretteteig et al., 2017; Lindauer et al., 2016; Adams & Sanders, 2004), and relationship once jointly shared with the caregiver (Tretteteig et al., 2017; Lindauer et al., 2016; Brunton et al., 2008; Adams & Sanders, 2004).

Some caregivers did not emphasise their care recipient's personality changes (Lindauer et al., 2016). For them, the care recipient's significance or value was instead considered to be of more relevance (Lindauer et al., 2016), than the

changes attributed to what has been lost to dementia (Lindauer et al., 2016). These caregivers therefore held on to “*what remained*” of the care recipient for as long as possible (Lindauer et al., 2016, p.738). A few caregivers however placed more emphasis on their care recipient’s lost personality (Adams & Sanders, 2004), instead of what remained (Lindauer et al., 2016). In comparison to those who considered the value of their care recipient to be of more significance, these caregivers regarded their care recipient as already gone (Adams & Sanders, 2004).

A commonality in the description of loss was therefore established as the recognition of the absence of care recipient’s valued personality (Lindauer et al., 2016; Adams & Sanders, 2004). Both of these studies also gave evidence of a common experience of a paradoxical feeling, described as holding on to ‘what remains of the care recipient’ (Lindauer et al., 2016), or holding on to ‘someone who was already gone’ (Lindauer et al., 2016; Adams & Sanders, 2004). These two expressions appear synonymous. However, while evidence of a historical hardship was cited between the caregivers and care recipients in Lindauer et al. (2016), the existence of such relationship was not described by Adams and Sanders (2004).

### **2.5.3 Grief: experiences at moderate and advanced stages**

Across the trajectory of dementia, variance in grief level existed (Lindauer et al., 2016; Adams & Sanders, 2004). As an emotional response to losing a loved one (Moore et al., 2017; Adams & Sanders, 2004; Colling, 2004), its severity was described as being at its highest at the advanced stage (Idura et al., 2018; Wladkowski, 2016; Adams & Sanders, 2004). In some cases, while caregivers’ perception of grief was regarded as part of the pre-death experience (Moore et al., 2017; Lindauer et al., 2016; Adams & Sanders, 2004), it was also associated with the observation of care recipient’s decline (Colling, 2004). Irrespective of the relationship

between the caregiver and their care recipient, the association between higher grief level and higher loss reported at the advanced stage was unclear.

Some caregivers reported a no-grief experience at both stages of dementia. At the moderate stage, for instance, this was considered a response to the delay in care recipient's decline (Adams & Sanders, 2004). As a result, caregivers at this stage concentrated on their care recipient's lost personhood as an outlet for their perceived loss (Adams & Sanders, 2004). Although this claim was also supported by Lindauer et al. (2016), both studies differed in some of their findings. While Lindauer et al. (2016) asserted that caregivers who reported a no-grief experience focused on their care recipient's personality which remained, Adams and Sanders (2004) reported that caregivers' emphasis was on their care recipient's already lost personality. The caregivers' no-grief experience was therefore related to anger, self-pity, or shame. (Adams & Sanders, 2004). On the other hand, the no-grief experience reported, especially by those with a shared history of hardship (Lindauer et al., 2016), establishes a defining characteristic of a shared identity.

Holding on to what remains caused caregivers' unpreparedness for their care recipient's death (Moore et al., 2017; Lindauer et al., 2016), as caregiver-attributed value was preserved longer. Indeed, for some caregivers, grief was irrelevant, and the reality of actual death was unacceptable (Lindauer et al., 2016). In this situation, a prolonged after-death grieving was therefore possible (Moore et al., 2017; Lindauer et al., 2016).

#### **2.5.4 Dealing with challenges and continuing with caregiving**

Some caregivers perceived their caregiving role as a natural obligation (Lindauer et al., 2016), and used religion to cope with their caregiving challenges (Idura et al., 2018; Lindauer et al., 2016; Colling, 2004; Smith et al., 2001). Through their religion, some perceived caregiving as rewarding or as the 'inheritance of good

morals' (Idura et al., 2018), while others considered it as fulfilling an important role (Lindauer et al., 2016), or doing the right thing (Tretteteig et al., 2017). These perceptions were common across both stages of the disease.

Caregiving expectations carried a sense of obligation (Idura et al., 2018), which was attributed by societal and cultural values (Chan et al., 2010), or caregiver's self-induced expectations to provide care (Idura et al., 2018; Tretteteig et al., 2017). This however varied with relationship between the caregiver and the care recipient (Idura et al., 2018; Tretteteig et al., 2017; Chan et al., 2010). In some societies, for instance, the obligation to provide care to older people was placed on their family (Lindauer et al., 2016; Chan et al., 2010) by sources such as the society (Tretteteig et al., 2017), religion (Idura et al., 2018), culture (Chan et al., 2010), a sense of history, and identity shared with the care recipient (Lindauer et al., 2016). In these societies, the perceived sense of duty, therefore, influenced caregiving (Tretteteig et al., 2017).

The fear of inadequacy in knowledge and skills existed in caregivers' preparation for their increased caregiving responsibilities (Idura et al., 2018). At the moderate stage, this was managed by finding a balance between the caregiver's expectation and the reality of care recipient's behavioural changes (Idura et al., 2018). Although some caregivers used their prior knowledge of the care recipient's background for managing challenges faced in caregiving (Colling, 2004), others considered care recipient's placement in a care home (Lethin et al., 2016; Adams & Sanders, 2004; Smith et al., 2001), or receiving support at home (Lethin et al., 2016). For most of the caregivers, placing the care recipients away from home was however inconceivable, especially at the advanced stage.

Caregivers' preference for continuing with home-based caregiving (Lindauer et al., 2016) was highlighted, especially in situations where the care recipient's decline necessitates the consideration for care provision outside of the home setting.

Caregivers often found this decision difficult as their wish to maintain control on caregiving persists (De Silva & Curzio, 2009). This wish to maintain control increased their ability to make meaning of the caregiving role (Tretteteig et al., 2017). Although this was considered a characteristic of caregivers' grief (Adams & Sanders, 2004), maintaining control was also crucial for balancing the caregiver-to-recipient relationship (Tretteteig et al., 2017).

Caregivers' loss of control was accompanied by a feeling of guilt and sadness, especially where the care recipient's placement away from home was necessary (Moore et al., 2017; Tretteteig et al., 2017; De Silva & Curzio, 2009; Adams & Sanders, 2004; Chan et al., 2004). The fear of poor caregiving by others outside of the home setting was cited (Moore et al., 2017) as a reason. Situations occurred whereby caregivers' guilt and sadness persisted beyond bereavement, due to self-blame (Moore et al., 2017). Although evidence was given which showed that this further increased the caregivers' reluctance to seek outside care away from home, the influence of the caregivers' perceived obligation to continue caregiving and their need to maintain control in such cases was however unclear.

Moving the person cared for away from home was difficult (Lindauer et al., 2016). Caregivers however used respite as their preferable means for managing their caregiving-related difficulty (Idura et al., 2016; Lethin et al., 2016). Generally, respite is used in briefly taking away caregiving responsibilities (de La Cuesta-Benjumea, 2011). Variation in its description, however, exists within the reviewed literature. According to Brunton et al. (2011), respite is described as a physical location, where care recipients reside in order for caregivers to have a break, or a situation where caregiving responsibility is shifted onto another person, such as a family member (Idura et al., 2018; Brunton et al., 2008). However, de La Cuesta Benjumea (2011) described respite as a situation whereby caregivers may separate themselves from their caregiving identity and briefly assume a different identity (de La Cuesta-

Benjumea, 2011). This therefore suggests that achieving rest is possible without the need for caregivers' physical separation from their care recipients.

Alternative identities were achievable through mental isolation, whereby caregiving responsibilities were mentally paused by the caregiver to give them an opportunity to explore other identities (de La Cuesta Benjumea, 2011). As such, managing caregiving challenges was possible, regardless of caregivers' physical location (de La Cuesta Benjumea, 2011). It is considered that this may be useful in situations where a respite facility is unavailable or where there is a reluctance to place the care recipient away from home (Lindauer et al., 2016; Brunton et al., 2008).

## **2.6 Discussion**

The purpose of this review was to understand how caregivers described their experiences of home-based caregiving at the moderate to advanced stages of dementia. Caring ensures a sense of commitment and responsibility with a focus on the well-being of a valued person (Swanson, 1993; 1991). Some positive aspects of caregiving were reported in this review, such as improvement to family inter-relationships (Idura et al., 2018; Chan et al., 2010), and caregivers' feeling of being useful and having a sense of meaning (Idura et al., 2018; Tretteteig et al. 2017). However, the central focus was mainly negative, and broadly on caregivers' experience of loss, burden, and grief. These experiences are reported in the wider literature as attributes commonly associated with the general experiences throughout caregiving for someone with dementia (Cheng, 2017; Chan et al., 2010; Adams & Sanders, 2004; Meuser & Marwit, 2001).

Meuser and Marwit (2001) suggest that there is an association between loss, burden, and grief of a caregiver. In this current review, the experience of these was not descriptive of all caregivers' narratives from the moderate to advanced stage. These are not the only dementia-caregiving related experiences, as others, such as stress,

anxiety and depression have also been reported (Blandin & Pepin, 2017; Chan et al., 2010; Adams & Sanders, 2004). However, the order in which these are experienced by caregivers remains unexplored.

Narratives of loss were explored from two different perspectives in this review. Firstly, loss was described in relation to caregivers' unmet needs, as a loss of social roles and difficulty in fulfilling own needs. This is termed '*personified loss*' in this review, as descriptions represented caregivers' perception of own loss. Loss was also experienced in relation to care recipient's changes and recognised as a caregiver-attributed value. This is termed '*personified value*' in this review.

The description of loss in terms of the caregivers' own needs has also been given in other studies. Brodaty and Donkin (2009) describe this in terms of a social isolation which may result in a loss of meaning in life. It is suggested this experience may worsen over time due to the possibility of an emotional burden exposure from increased caregiving (Greenwood et al., 2019; Brodaty & Hadzi-Pavlovic, 1990). Similar findings have also been reported in this current review. Changes to the caregivers' way of life were described by their increased burden through caregiving responsibilities (Chan et al., 2010; Colling, 2004). Also, their inability to socialise at this stage of dementia was viewed as a conflict between increased psychosocial distress and associated changes to caregiving focus (Chan et al., 2010). In relevance to this experience, the description of caregivers' *personified loss* may therefore be a precursor to a *personified cost* in terms of opportunities forfeited for accepting caregiving responsibilities. Hence, the likelihood of the caregivers' *personified loss* being interpreted as a forfeited way of life rather than expressed as part of the normal progression of dementia caregiving is elevated.

Loss was described as a caregiver-attributed value in this review. In similarity to this description, Dupuis (2002) identify this as a detrimental attribute due to the possible

closeness between the caregiver and the person cared for. This loss was further described in terms of an ambiguity given that it acknowledges the absence of a valued personality (Dupuis, 2002). This ambiguity of loss has also been explored by Boss (1999) and Jones and Martinson (1992). Similar to the findings of Dupuis (2002), evidence from these studies suggest that caregivers experienced a state of loss where the person cared for was considered gone while still physically present. Similar findings are also presented in this review. Although this was described as loss of *personified value* in this present review, the description of the person cared for as 'already gone' while still alive was also reported.

The possibility of increasing caregivers' emotional hold on personalities that remains is a reality, given caregivers' fear of losing *personified value*. Subsequently, holding on persists longer, as a paradox where balancing "*what remains*" of the care recipient with "*what is already lost*" becomes difficult (Lindauer et al., 2016; Adams & Sanders, 2004). As in other terminal conditions, evidence suggest that this experience, also referred to as anticipatory grief, is a pre-death response to the process of progressive decline in dementia (Pérez-González et al., 2021; Cheung et al., 2018; Blandin & Pepin, 2017; Meuser & Marwit, 2001). Thus, in cases where the realisation of dementia caused the *personified value* to be attributed early on, it is plausible that caregivers' fear of losing *what remains* may cause a higher level of grief in both stages.

The risk of health complications from earlier stages of the disease and possibly post-death may also increase. The resolution of grief corresponds with caregivers' acceptance of own loss (Prigerson & Maciejewski, 2008), and "*an emotional inability to accept the loss of something cherished*", results in grief and its attributes such as guilt, frustration, and helplessness (Prigerson & Maciejewski, 2008, p.435). While grief is described as a natural response to caregiver's loss (Rando, 2000), those who report higher levels of pre-death grief have a higher risk of health complications post-

death (Shuter et al., 2014; Chan et al., 2013; Givens et al., 2011). Resolution of caregiver-attributed *personified value* is therefore necessary.

Grief was not an experience reported by caregivers who shared a historical hardship with the care recipient in this review. In commonality with other caregivers, holding on to *personified value* for longer was highlighted. While it is appropriately assumed that “*something cherished*” may refer to factors such as caregivers’ time, freedom, or care recipient’s value, as well as the identity shared as a result, the loss described may therefore also be personified. Further research is, however, required for differentiating between a caregiver-attributed value of what remains of a care recipient and what is already lost to dementia, and its influence on the possible duration of prolonged after-death grieving.

It is also appropriate to consider that for most caregivers, a grief-experience is reported through both stages of dementia irrespective of their relationship with the care recipient (Meuser & Marwit, 2001). As the care recipient declines, *personified loss* increases in line with the increased demand for caregivers’ attention (Colling, 2004). Consequently, loss of *personified value* and caregivers’ grief may also increase at both stages. The justification and determinants for balancing *personified value* against caregivers’ *personified loss* are however currently unclear. Given these findings, the issue of balancing caregivers’ reported experiences against their reasons for continuing caregiving at both stages of the disease therefore arises. It is assumed that other factors may also be present in the caregivers’ experiences, whereby powerlessness is felt in how future priorities are perceived and how the balance between *personified value* and *personified loss* may influence continued caregiving. This also calls for an understanding of a possible caregivers’ distress at choosing the right course of action to take in such situations (Oh & Gastmans, 2015; Silén, 2011; Jameton, 1993; 1984).

## 2.7 Gaps in knowledge

Some gaps in current knowledge were identified during this review. It was claimed that variation in caregivers' grief-experience across dementia stages (Lindauer et al., 2016; Adams & Sanders, 2004) increases with severity (Idura et al., 2018; Wladkowski, 2016). Also, a higher level of grief-experience is associated with the advanced stages (Adams & Sanders, 2004). Clarity is however required to determine whether higher grief level at the advanced stage is as a result of the higher loss from the earlier stages.

Second, it was reported that caregiving expectations placed from different sources induced a sense of obligation on caregivers (Idura et al., 2018; Tretteteig et al., 2017; Chan et al., 2010). This varied according to the relationship between the caregivers and their care recipients (Idura et al., 2018; Tretteteig et al., 2017; Chan et al., 2010), and serves as a factor which influences caregivers' behaviour (Tretteteig et al., 2017). While the possibility of negative outcomes was reported, the relationship between caregivers' obligation and grief level remained unexplored. Although similarity of experience of holding on to care recipients' personality was evidenced in the literature, an ambiguity existed between clear definition of what remains of the care recipient (Lindauer et al., 2016) and what was already lost to dementia (Adams & Sanders, 2004), as well as its influence on determining the duration of prolonged after-death grieving.

## 2.8 Implications

The impact of higher levels of pre-death grief in caregiving for someone with dementia is widely recognised in association with health complications post-death (Shuter et al., 2014; Chan et al., 2013; Given et al., 2011). Although higher grief level is commonly attributed to the advanced stages, the possibility of attributing a *personified value* earlier in caregiving is evident from this review. For the caregiver,

the fear of losing the care recipients' *personified value* carries a higher level of grief in both stages, thereby increasing the risk of health complications earlier and possibly post-death. This may influence how home-based caregiving is viewed by caregivers and their willingness to accept or continue caregiving responsibilities at home. Given a projected increase to over two million dementia caregivers by 2051 (Knapp et al., 2014), the implication is therefore severe for sustaining home-based caregiving for people with moderate to advanced dementia in the UK.

## **2.9 Strengths and limitations of the review**

The adoption of a narrative synthesis approach allowed for heterogeneity of evidence in this review. This approach may have contributed to the robustness of synthesised evidence. A difficulty in managing the scope of possible evidence was however high, as a large number of individual papers were checked for the inclusion criteria to be met. This difficulty was further exacerbated by the inaccurate classification of some papers by their authors, thereby making inclusion difficult from reading their abstracts. It was further considered that variation of accounts contributes to how the experience of caregivers' loss is explored in future research. Given that some accounts used were extrapolated from a wider context of discussions within the reviewed literature, full justification of accounts may be difficult (Polit & Beck, 2010). Generalisation of the findings at either of the moderate and advanced stages of dementia may therefore also be difficult. However, the main purpose of any qualitative endeavour, such as this review, is to provide a rich understanding of people's accounts. Polit and Beck (2010) highlight that the transferability of these accounts across clearly defined settings and contexts is therefore appropriate.

## **2.10 Conclusion and recommendations**

An understanding of the current literature is critical to all phases of a review. In this present review, this ensured that the gaps in current knowledge were highlighted on

the wider context of dementia caregiving within the domestic home setting. The identification of existing studies therefore contributed to the originality of the review and avoided duplication. The review adopted Popay et al. (2006) narrative synthesis approach in exploring how family carers described their experience of providing home-based caregiving for people with moderate to advanced dementia. Caregivers' descriptions of experiences at the moderate to advanced stages of dementia may vary. The overall accounts reported suggest that spending time with the person cared for enhances the acknowledgement of the illness experience by the caregiver. Within the moderate to advanced stages of the disease, these accounts of experiences appear to align with some of Swanson's (1991;1993) understanding of the caring process more than others. This may suggest that as time is spent by the caregiver in providing care, while homebased caregiving for people with dementia may be described through the experiential inputs of their caregivers, a complete description of all experiences may not be necessary in justifying the full extent of caregivers' acknowledgement of the illness. It is likely that the level of understanding of the illness experience also differs. In this review however, the caregiving experiences have been discussed through the accounts of caregivers' burden, loss, grief, and how they deal with challenges in making meaning and continuing in their caregiving role.

While increasing caregiving responsibilities increased caregivers' difficulties, especially at the moderate stage, experiences of their loss through to the advanced stages is also crucial. In some cases, their actions indicated that the caregiver-attributed *personified value* resulted in holding on to what remains of the care recipient for longer, thereby causing an experience of a higher grief level that may start from the moderate stage or earlier. More knowledge is therefore required to ascertain how caregivers may proportionally balance their *personified loss* with their *personified value* earlier in the disease trajectory. This is imperative, given that the full justification and the determinants for balancing these, and whether a distress to

morals is felt, remains unclear. Conducting a further empirical study is therefore warranted.

## **Chapter 3: Research design and methodology**

### **3.1 Introduction**

The purpose of this study was to explore how family carers describe their experience of a home-based caregiving for someone with moderate to advanced dementia towards the end of life. Narrative synthesis of the literature has highlighted the different methodologies that have been adopted in the exploration of family carers' experiences of home-based care for people with moderate to advanced dementia. The relationship between the care recipient and the family carer may influence a sense of obligation which is induced by caregiving expectations from different sources. This may also influence the family carer's behaviour.

The philosophical and epistemological stances are positioned in this chapter. The rationale for narrative inquiry design selected as the methodological approach to study conduct is also explored. Issues of reflexivity are also later discussed as a method for presenting transparency and trustworthiness of the research process. Steps taken in ensuring rigour in the research process are also highlighted, thereby giving evidence of the appropriateness of both the methodology and methods adopted in answering the research question.

### **3.2 Epistemology**

This study was informed by social constructivism, a theory centred on the lived experiences of people within their society, which exists both as a subjective and objective reality (Andrews, 2012). According to Riessman (1993), narrative research is associated with the constructivist epistemology. As a methodological approach for understanding the nature of reality, social constructivism may also be regarded as a reflection of what is being observed (Andrews, 2012; Murphy et al., 1998). This description of social constructivism may however give an indication of reality as a

fixed construct. It may also imply that there is only one truth in accounts of experiences. However, social constructivism also adopts a relativist position which assumes the capability of reality being created socially, and hence, the rejection of reality as an absolute. In this regard, the implied notion of a fixed reality and singular truth is rejected as the description of an experience varies from one person to another. Reality may therefore be regarded as a construct created from social experiences, from which shared meanings may also be derived (Andrews, 2012; Guba & Lincoln, 2005; Schwandt 2000).

The aim of this study is to explore the experiences of family carers for people with a moderate to advanced dementia within the domestic home setting. While the investigation of shared experiences falls within social constructivism, the approach to its use in research as an inductive process also recognises the researcher's own perception of a phenomenon (Creswell, 2003). This is also useful in understanding of socially constructed meaning through the dialogic process of co-construction between the narrator and the interviewer (Riessman, 2008).

### **3.3 Research design and rationale**

The use of quantitative studies was excluded in this research given its purpose, which was to explore how family carers describe their experience of home-based caregiving for someone with a moderate to advanced dementia towards the end of life. Finlay (2009) highlights that this subjective meaning of a phenomenon is better understood through the description of lived experiences. This qualitative focus also suggests that design approaches such as grounded theory (Charmaz, 2000) and descriptive phenomenology (Giorgi, 2009) should be considered. Descriptive phenomenology is a *“direct exploration, analysis, and description of particular phenomenon, as free as possible from unexamined presuppositions, aiming at maximum intuitive presentation”* (Spiegelberg, 1975, p.64). Grounded theory, on the

other hand, is based on a constructivist epistemology and encourages the interaction between the researcher and the participants (Charmaz, 2000). There are, however, no set rules for identifying categories of experiences explored using this method.

A phenomenological design by Giorgi (2009) is an approach that may initiate a research process from a researcher's bracketing or elimination of assumptions. The robustness of the data analysis process suggests that accounts from a small sample of participants may be useful. However, by employing a lengthy method of data collection, this design approach may be limited to the description of experiences and not for interpretation of meaning (Englander, 2012; Omery, 1983). The exploratory focus of this current research was considered in the choice of design and strategies by which the research question may be answered. Based on the epistemological position, which considers that the subjective meaning of a phenomenon is better understood through individual stories (Barrett et al., 2007; Fossey et al., 2002), a methodological approach guided by Riessman's (2008) narrative technique was therefore adopted through unstructured interviews.

### **3.4 Narrative inquiry**

Narrative inquiry is the acquisition of relational meaning of interactions between an individual and their experience of a particular phenomenon over time (Clandinin & Connelly, 2000). The possibility of this interaction through storytelling during a narrative inquiry, such as in this study, aids the creation of meaning through the narrator's ability to position themselves in specific time and space, while giving an account of a phenomenon (Bamberg & Demuth, 2016). The capability of this interaction in giving form to individual experiences helps in understanding what happened and why (Bamberg & Demuth, 2016). In this study focused on understanding the specific experience of family carers who provide care to people with a moderate to advanced dementia within a domestic home setting, this premise

was useful in understanding their account of events with respect to time and the disease trajectory. The understanding created was ontologically congruent with the social constructivist epistemology adopted for the study.

The technique by which researchers can interact with the collected data during the narrative inquiry depends on the adopted methodology (Nowell et al., 2017; Braun & Clarke, 2006). Narrative design methodology by Riessman (2008) stresses that the approach adopted in understanding the data must not only be interested in, or restricted to structural appraisals of the participant's narrative, which explores sequence of events as told by the participant (Gee, 1991; Labov, 1982). It must also not be restricted to the dialogical analysis of the account (Bell, 1999), which explores only the dialogue between the researcher and the participant. The subjectivity of the narrator in the describing their individual experiences plays a crucial role in creating useful meaning from collected accounts. Using Riessman's (2008) design approach therefore suggests that narrators are able to convey their point by relating events through time as they tell their stories.

Riessman (2008) considers that the use of the narrative technique to explore participants' experiences must ensure that due cognisance is given to the researcher's declared ontological and epistemological stances. In this study, consideration for how the participants narrated their stories, the contents of the stories told, as well as a dialogical relationship between them and myself as the researcher during narration was noted in detail. By taking these steps, the meanings of both their individual and collective narratives were possible from first-hand account of their narrated experiences.

### **3.5 Conclusion**

The rationale for the research design and methodology has been explored in this chapter. It has been established that adopting an epistemological position in a narrative inquiry is crucial. However, this implies the trustworthiness of the interpretation of the findings through the persuasive capabilities of the researcher. Trustworthiness of findings was however established through the transparency of the processes followed in the conduct of this study, including the use of verbatim transcription of collected data which further establishes rigour in the research process.

## **Chapter 4: Research methods**

### **4.1 Introduction**

The justification for adopting narrative inquiry as a method for conducting this study has been described in the previous chapter. In this current chapter, the research population, sample and methods adopted for recruitment of study participants are described. Some of the difficulties encountered in recruitment and methods by which these were resolved are also discussed. As a narrative method was used in analysis, transcription of collected data was necessary, as well as a method for managing this data given the volume of the data collected in the interviews. Issues of potential harm through a break in confidentiality were addressed by ensuring anonymity of participants' data following data collection.

### **4.2 Population**

The population of interest for this study are family carers for people with a moderate to advanced dementia. Family carers are generally described as family members, friends, relatives or anyone who provides an unpaid but significant care for an ill person (Woodman et al., 2016). For the avoidance of any ambiguity, family members who acted in the role of caregivers were regarded as those related through committed heterosexual or same sex partnerships, birth or adoption, and others who had strong emotional and social bonds with the care recipient. Other carers who were either family members or not, were regarded as lay, unpaid individuals in a close supportive role, who shared in the illness experience of the person receiving care. Co-residency with the care recipient was not mandatory for study participation, although it was necessary for the care recipient to have either been receiving care from the caregiver in a domestic home setting at the point of interview or having received such care within six months prior to the interview date. The inclusion and exclusion criteria are further described in Table 4.1.

Table 4.1: Study inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
a) The carer is a family or family carer for a person within the moderate to advanced stages of dementia. Dementia stage is supplied by the caregivers during pre-interview eligibility check.	a) The family or family carer lacks capacity to consent to participate.
b) Care is currently provided by the family carer or has been provided in a domestic home setting to the person living with dementia within the past six months.	b) The family or family carer has insufficient English language skills to participate in an interview.
c) Family carer is aged 18 or over.	
d) Family carer can supply information on dementia stage.	

### 4.3 Sample and sampling strategy

There is no consensus for sample size determination in qualitative studies. Due to the nature of a qualitative inquiry, sample sizes are therefore usually small (Sandelowski, 1995). Both Guest et al. (2006) and Bertaux (1981) suggest that all qualitative research inquiries should have a sample size of at least 15 participants. For this present study, evidence from similar narrative studies show that the determination of an appropriate sample size varies between eight (Lee et al., 2013; Ellis-Hill et al., 2000) and 15 (Nicholson, 2009). A sample size of 15 participants was therefore likely to be sufficient in producing a quality and rich representation of accounts of home-based caregiving.

The sample was purposively selected based on the commonality of home-based care experience for people living with dementia between the moderate and the advanced stages. Using this strategy ensured that the participants had the relevant experiences required as the basis for in-depth narratives (Patton, 1990). It was anticipated that the medical records for the care recipient may be difficult to access or not readily

available. As such, information provided by the caregivers during the pre-interview eligibility checks was deemed sufficient given their in-depth knowledge of the dementia-related changes in the person cared for over time.

#### **4.4 Recruitment**

The emotional strain of caring at home for people living with dementia makes it sensitive in nature for the caregivers. This may suggest a likely difficulty in finding potential participants for the study, given the long hours of caring (Brodaty, 2009). Evidence shows that family carers are likely to engage with community-based services either focused on the caregivers themselves, such as carer support groups, or the person cared for, such as health and social care services (Quince, 2011). The likelihood of a good response from the family carers at these locations was therefore anticipated, and both direct and indirect approaches such as distributing flyers, leaflets and posters were used (White et al., 2018; Feldman et al., 2008).

Potential participants were identified through a number of different routes including domiciliary care agencies, care support groups and Join Dementia Research:

- a) Domiciliary care agencies: potential participants were identified by the care agency and provided with a study pack by the agency manager.
- b) Carer support groups: potential participants were identified by the group coordinator and supplied with a study pack.
- c) Join Dementia Research (JDR): this is an online self-registration service that enables carers of those with memory problems or dementia and healthy volunteers to register their interest in taking part in research.

Once potential participants had received initial information pack about the study, they could register an expression of interest in participating or ask to receive further information by contacting the researcher by telephone, sending an email, or returning a reply slip. This multifaceted strategy ensured the identification of a variation of

potential sites. The avoidance of an over-reliance on recruitment from a single location was also ensured, as this may have excluded a variety of experiences from being accessed. (See Appendix 3 for the information pack.)

The identification of potential participants varied between the organisations. For the domiciliary care agencies and carer support groups, the agency manager and the group coordinators were crucial in initially introducing the study to potential participants. The JDR however allowed for registered volunteers to be identified by the researcher as potentially eligible for participating in the study. The potential participants' preferred method of contact was used to discuss their potential inclusion. Some of these contacts were unsuccessful although study information packs were provided. In accordance with JDR regulations, it was assumed that these volunteers had no interest in taking part and all unsuccessful attempts were recorded on the JDR website. Where a volunteer was unavailable to receive a telephone call, voice messages were not left.

Following a confirmed interest in taking part, eligibility screening was conducted as a telephone call to the potential participant. The purpose was to ensure that participants met the inclusion criteria before an interview date was set. This was crucial in establishing a potential participant's relationship with the person cared for, and to ascertain the stage of the illness. The date and location of the interview were mutually agreed at this point. This screening process took between 15 and 25 minutes. A consent form was supplied either by post or in an email from the researcher following an expression of interest by potential participants. This form provided information indicating how to give consent to take part, and the right to withdraw from the study either before or during the interview.

Written consent was obtained in all cases. In situations where an interest was expressed but the consent form was not returned before the agreed interview day,

written consent was obtained before the interview commenced. Verbal consent was sought before commencing the interview. As a process of progression during the interview session, further consent was verbally requested at each stage of the interview to ascertain the participants' willingness to continue with the interview session. This process only took about 10 minutes. The overall recruitment process took place over a period of 12 months and ceased once an adequate sample size had been interviewed. The eligibility and consent forms are presented in appendices 4 and 5.

#### **4.5 Data collection and management**

A narrative technique was employed to collect data from study participants. Using narrative interviews in qualitative research has been described in terms of the emergence of individualised reality in the description of a phenomenon (Muylaert et al., 2014). Within its discursive approach, Muylaert et al. (2014) describes the unstructured format as important in empowering the respondent's account of an event. The significance of the language employed is further described in terms of a partnership between the interviewer and the respondent in co-production of reality from the respondent's varied experiences (Riessman, 2000). Data collection took place within a domestic home setting in all cases on a date mutually agreed between the researcher and the participant. The process started with the researcher obtaining a written consent from the participant prior to interview commencement. Interviews were conversational in style, a data collection approach regarded as a natural extension of the narrator's observation, and natural flow of researcher-narrator interaction (Patton, 2002). This approach draws strength from the spontaneity of natural questions' generation (Patton, 2002). A single interview session was conducted with each participant.

A topic guide was used for guiding data collection in this study. This encouraged the discussion of participants' experiences through their stories, and in their own words. According to Zhang and Wildemuth (2009), a topic guide is a broad agenda of areas that may be covered in an interview. Covell et al. (2012) suggest that the topic guide questions should not be framed in any way that may influence participants' responses. By allowing the description of the narrator's experience in their own words, the natural emergence of stories was encouraged (Riessman, 1993). During data collection, the guide was adapted by the researcher with follow up questions and prompts based on participants' responses to each topic in order to elicit further information. This process was repeated for each topic until interview completion. The flow of the narrative was not interrupted, and points that required further elaboration were followed up later in the interview. It was necessary in some cases to ask for further clarification on certain viewpoints the participant expressed during the interview. These were asked with phrases such as 'tell me more about that'. (See appendix 6 for the topic guide).

Collected data were recorded using a portable encrypted digital recorder and immediately transferred to an encrypted and password-protected hard drive at Lancaster University. Identifiable details used in contacting the participants for arranging interview date and location were stored away from data in a locked cabinet. Original audio recordings were deleted from the portable digital recorder. A password-protected home computer and laptop were used for data processing during the study. To ensure confidentiality, participants' personal details were kept separately from interview data, which were stored as a separate secure file at Lancaster University.

## 4.6 Data analysis

According to Riessman (2008), a single approach to narrative analysis does not exist. Narratives provide an insight into the narrator, and the focus should be on *“the act the narrative reports and the moral of the story”* (Riessman, 2008, p.62). The decision on a specific analysis approach to follow remains the researcher’s responsibility. In Riessman’s (2008, p.13) view, a good narrative analysis *“prompts the reader beyond the surface of a text, and there is a move toward a broader commentary”*. Thus, analysing the data narratively should provide a means for constructing meaning from the narrators’ told stories. Olken (2015) however cautions about having a pre-specified chain of steps for analysing the collected data, given the unpredictability of the outcomes following analysis. The eagerness to make sense of the collected data meant that caution was necessary to avoid an induced bias, given the researcher’s professional knowledge of family carers’ input in home-based dementia care.

During the data analysis stage, two questions became apparent. First, are the participants able to give a good representation of their own stories? Second, how credible was their account during the interview? A search of the literature however showed that these lines of inquiry are not new in qualitative efforts adopting a narrative methodology, such as this present study (Muylaert et al., 2014; Kirkevold & Bergland, 2007). The accuracy of the narratives given by the participants was not a concern as they were purposeful and provided as a reconstruction of the experiences of the teller. While these accounts may not represent life as lived in some instances, such as telling stories from the care recipient’s point of view, they however present the lived experiences as recounted by the narrator (Etherington, 2013). They may also be regarded as a means of depicting a picture of self and identity in the participants’ narratives.

The inherent nature of the possibility of a multiple interpretation during data analysis in the narrative method is noteworthy. In this regard, it is pertinent for the researcher to understand that under different interview conditions, such as a change in the interviewer, the framing of the questions asked, or the purpose of the interview, distinctively different accounts may be given by the participants to similarly composed questions. In all cases however, it is necessary to note that there is integrity in the participants' accounts, given the subjectivity of their lived experiences. Their mimetic representations of life as told are therefore credible for the specific discussions during the interviews in this study (Riessman, 2008). Furthermore, they are necessary for the integrity of their accounts in how their data were later analysed.

#### **4.6.1 Transcription process**

Transcription is an interpretative process (Reissman, 2008; Green et al., 1997; Mishler, 1991). Contrary to the common perception of being a monotonous and boring process, it is regarded as the first step for self-familiarisation with the data for the purposes of analysis and interpretation of the transcribed text (Braun & Clarke, 2006; Jovchelovitch & Bauer, 2000; Riessman, 1993). The first stage of the analysis approach required that the audio interviews were transcribed once completed. The transcripts generated from these interviews were the verbatim discussions between the participants and I as the interviewer, as well as the emotions expressed during our discussions.

In the transcripts, participants' hesitations, false-starts and pauses between sentences helped with the interpretation of their data and were regarded as conversational breaks (Gee, 1991). These were also considered a common feature of spontaneous speech and as attributes of natural social interactions (Shriberg, 2001; Rose, 1998; Goodwin, 1980). According to Riessman (2008), these show how personal narratives are social at many levels. Verbatim transcriptions were produced

to ensure that representation of participants' attributes during the interview was accurate. My input was transcribed as evidence of my presence and collaboration throughout the interview. In the generated transcripts, I was referred to as 'CJ' and the participants' details were anonymised using a letter from within their name and a number which represented the numerical order of the interview.

Evidence of disorder and messiness of qualitative data from interviews is well documented (Breen, 2006; Irvine & Gaffikin, 2006; Mellor, 2001). Once the interviews had been transcribed, a data cleaning process was undertaken in the second stage to smoothen out some of the conversational breaks and pauses. It is pertinent to differentiate between this approach to data cleansing and the technique for identifying and correcting errors in data. While the latter seeks to minimise the impact on study findings (Chu & Llyas, 2016; Van den Broeck et al., 2005), the purpose of the former was to make the transcript easier to read and understand for analysis purposes. This process, also known as restorying (Riessman, 2008), demonstrates the significance of memory's role in providing insights into identity building as well as placement over a life course (Riessman, 2008).

These insights, according to Riessman (2008), are useful in shaping how the narratives developed during the interview and how these were later analysed. Narratives are given in the form of stories (Stapleton & Wilson, 2017; Hargood et al., 2011). This was evident in the interviews as narrators talked about a series of occurrences and events. At times, several events were given as intertwined stories. Some of these were given in time order, while others were recounted. Arranging these stories in time order while possible, was however unnecessary to preserve data integrity. The transcripts were therefore analysed in the same order in which the narratives were given.

According to Riessman (2008), transcription is an essential step in analysing gathered information. However, there is no standard set of processes for conducting a narrative analysis, as is the case with other types of qualitative endeavours (Riessman, 1993). The interpretative nature of the transcription process suggests that the selective attribute of audio-taped interviews makes it difficult to capture significant features such as gestures, participant's facial expressions and other features in generated transcripts (Riessman, 2008). Hence, it is possible for the same narratives from a participant to be interpreted differently based on the differences in theoretical and methodological approaches adopted (Riessman, 2008). The participants' verbatim interactional transcripts generated and their prior consent to take part in the study were therefore sufficient for the integrity of their accounts as an "*auto-biographical self*" (Riessman, 2008, p.29).

#### **4.6.2 Analysis plan development**

A plan for analysing the transcripts of the audio-taped interviews was developed based on Riessman's (2008) guidance. Crucial to this process was my understanding of the narrators' stories and acceptance of their integrity and deserving agency over their own stories as told (Yardley, 2006). A two-stage approach to data analysis was followed by first transcribing the participants' interviews, and restorying the transcribed version. In Cudworth's (2014) view, this process involves the reorganisation of a prose form of the final transcripts into fluent versions of their pre-organised state. However, participants' input was not engaged in the production and editing of the transcribed version of the interview. While this may have demonstrated co-construction, the reliance on participants' availability and willingness to engage with their previously given interview was acknowledged. Post-transcription confirmatory comments may therefore have not been feasible within the study timeline.

Post-transcription verification of accounts is usually preferred by narrative researchers in terms of accuracy and possibility of gathering additional comments (Cudworth, 2014; Hagens et al., 2009). The validity of this method has however been questioned (Riessman, 2008; 1993). Citing the likelihood of a participant's lack of comprehension of the findings drawn across multiple narratives, a researcher's readiness to be accountable for the analysis of the collected data is advocated (Riessman, 1993). It is likely that post-transcription verification questions the participants' integrity of their original stories as told during the interview. It is posited therefore, that where verbatim transcription is used, true account of participants' personal experiences should be derived from the spontaneity of their own stories as told, rather than as imposed by the researchers' need or desire for further verification of account.

#### **4.6.3 Transcript restorying**

Restorying, according to Riessman (2008), begins with eliminating the involvement of the interviewer in the discussions and 'cleaning' the transcript produced from the interviews conducted. Riessman was however mindful that this may cause controversy in how some readers rationalise the interviewer's exclusion within co-construction, being one of the fundamental principles of the narrative technique. The appropriateness of this approach is argued for its' interpretative ability in presenting the story as if "*full blown from within the self of the speaker*" (Riessman, 2008, p.35). It is possible, however, for restorying to lead to a new story being created given that rich details are added by the researcher (Ollerenshaw & Creswell, 2002). While post-interview verification by the participant may maintain the authenticity of collected data, it also implies that only "*a single true representation*" is possible (Byrne, 2017, p.38).

The steps involved in restorying were not clearly defined by Riessman. A clear guidance was also not found in the literature. A closed-loop protocol was therefore developed for this study as an iterative approach involving both transcription and restorying. Using this method, transcribed interviews were restoried by smoothing out only some of the conversational breaks and pauses (e.g. umm, uhh, mmm, you know, yeah) to ensure clearer readability. The process holds true to the original narrative since participants' verbatim responses are kept, thereby preserving data integrity. The protocol can be adapted to generate multiple narratives from the same transcript, while saving time in its applicability for manipulating transcripts during the restorying process (see Fig 4.1).

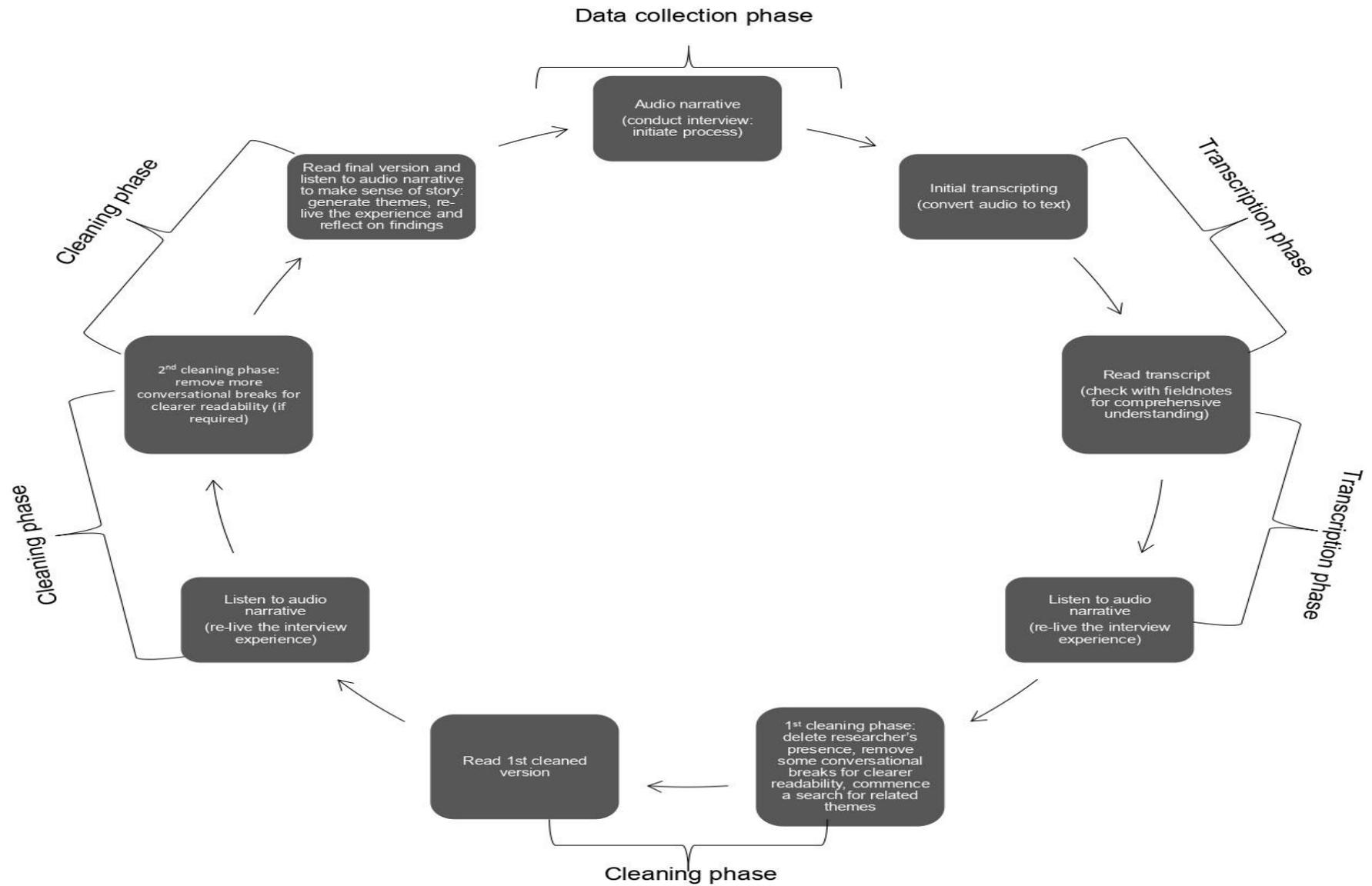


Fig 4.1: The closed-loop cleaning process

#### **4.6.4 The closed-loop cleaning process**

According to McCormack (2000), participants' stories are re-lived as a reconstruction and re-interpretation of their experiences during interview. It was understood that in the participants' stories through which their caregiving experiences are reflected, the researcher was only granted access to an imitation, which is a recollection of experiences (Riessman, 2008). As an interviewer, the researcher was considered a 'conduit' through which the stories are re-told, and effectively became part of the construction of the narrative. For the avoidance of a researcher-induced bias (Pannucci & Wilkins, 2010), the credibility of their stories as told, lies in the transparency of the methodology adopted. As an audience within their story, the researcher was therefore compelled to accept the subjectivity of their experience and the mimetic positioning of their narrative as an imitation of their lived experiences. Seidman (2006) agrees that this is crucial in understanding the ontology or the nature of the reality of their narrated stories.

While conducting the analysis of the transcribed data, the researcher re-lived the narrators' moment-by-moment descriptions of their experiences as told during the interview. This was necessary in relation to the researcher as a 'conduit' for re-telling the stories post-analysis. This involved systematically listening for my own voice as the researcher, but more importantly, the participant's voice in the audio-taped interview to ensure the effectiveness of the unbiased data cleaning approach adopted. In Sutton and Austin's (2015) view, participants' words can be better interpreted and reported for others to learn by hearing their voice. Through hearing ones' own voice in the interview, the authenticity of the interview is supported and may be used as a basis for the cleaning process (Padgett, 2016). Re-living the interview experience therefore reaffirmed the narrator's authorisation for their story to be told and may be useful in cases where future confirmation of transcribed interview

is impossible. An original transcript from the interview with participant A1 is presented in Appendix 7. A restored copy of the same transcript is shown in Appendix 8.

#### **4.6.5 Process for analysing participants' responses**

Interview transcripts were initially uploaded into Nvivo software for management. Using this software, a thematic analysis approach by Riessman (2008) was adopted in exploring participants' responses. With this approach, a complete interview was treated as the unit of analysis without segmentation (Riessman, 2008). The purpose was to ensure the preservation of the richness of the diverse stories told in each narrative. Phrases which stood out in each story embedded within the narratives were first identified. These were considered threads through which themes may be derived. Notes were attached to these threads to clarify the researcher's thoughts on individual stories within each narrative.

The patterns within each narrative were carefully followed by making note of the overarching focus of the whole narrative. By following such methodical approach, it was easier to understand where the same pattern exists across all narratives and what differences were exposed between their individual narratives. It was easier to present the findings as two parts. In the first instance, a narrative heading was introduced, and subsequent patterns found within these narratives were presented using participants' verbatim quotes in support of the evidence. Chapter 5 of the thesis presents each of these narratives in detail.

#### **4.6.6 Evidence of co-construction**

Co-construction is a collaborative process between the participant and the researcher in making meaning from stories of personal experiences (Riessman, 2008). As evidence of this joint collaboration, questions were asked as interjections to participants' responses throughout the interviews in this study. This gives evidence of the varied perspectives of the participant's self, which does not only exist in its pre-

interview state but is capable of being co-constructed through independent social interaction (Riessman, 2008). The presentation of the participant's autobiographical self, reflecting how they wished to represent themselves in their stories, was therefore possible. Co-construction was also authenticated by this collaborative presence in the presentation of findings as a biographic account of the participants' narratives using their quotes and verbatim words in representation of their stories.

The messiness of presenting findings from the analysis of life stories is clear as a possibility of raising more questions than answers. Sutton and Austin (2015) highlight the usefulness of providing more context for the readers, Chan (2017) further considers their discursive nature in making participants' narratives more understandable. As the researcher and the interviewer, it is possible for this interpretation of participants' narratives to be different from another researcher's interpretations. As guided by Riessman (1993), the researcher accepts complete accountability of this analysis of participants' data as a representation of the narrators' identities and experiences through their storied narratives.

#### **4.7 Reflection on the analysis process**

The researcher's competence in conducting the interviews with regards to issues of sensitivity and possible distress to the participant is evidenced by the years of professional experience gained in working with people living with dementia and their family carers, as well as the extensive training undertaken as a pre-requisite to progression on the PhD programme at Lancaster University. The sensitivity of the changing situation of caregiving, especially the long duration of caregiving in dementia compared with other illnesses (von Känel et al., 2019; Shih, 2016; Tremont, 2011; Brodaty & Donkin, 2009) therefore influenced the decision taken against approaching study participants for further comments post-transcription.

Difficulty was initially encountered in finding suitable phrases to easily summarise themes from individual narratives. Uncertainty on the best method for presentation of findings and a difficulty in clear representation of a collaborative evidence of co-construction was encountered. During the analysis, an assumption was made of an easy method for finding words which expressed internal conflicts and, in some way, explain the experience of moral distress. Although the experiences of internal conflicts were clearly expressed across most narratives, the complexities of moral distress made it more difficult to understand. However, the family carers' experiences mirrored the findings reported in the literature review in Chapter 2, in terms of burden and the experience of loss.

#### **4.8 Ethical considerations**

The underlying principles of ethics in research involving human participants are guided by values which seek to promote good outcomes while preventing harm to the participants during the research conduct (Veatch, 1988). Ethical issues encountered in research involving caring for people with dementia mainly arise from a personal context, and the caregiver's wish to protect the care recipient's interest may be evident. Hughes et al. (2002) suggest that this may be due to the enduring relationships in family carers' experience. Final ethics approval was granted for the study by the National Research Ethics Committee (Ref: 18/WM/0001) on 22<sup>nd</sup> November 2018 following the submission of the research proposal and necessary amendments (see ethics approval in appendix 9).

Ethical principles require avoidance of harm at all costs (Watts, 2008). Study participants' experience of a minor psychological discomfort, especially during an interview was possible. It was anticipated that psychological discomfort would be evident through verbal indication of emotional distress. Verbal consent would therefore be necessary when emotional upset was observed. The possibility for a

participant to quickly go from a mild to a severe state of distress was also anticipated. A distress protocol from Draucker et al. (2009) was therefore adapted for use in the present study. It was anticipated that should a situation occur whereby the distress protocol should be triggered, the interview will be terminated immediately, and actions suggested in the protocol followed. As caring for people with dementia could be challenging, especially during the later stages, a protocol was developed for assessing a possible disclosure of information which may suggest that major difficulty is experienced in care provision (see the distress and disclosure protocols in Appendices 10 and 11).

For the avoidance of coercion, participation in the study was voluntary and consent sought prior to taking part. Participants retained their right to withdraw from the study either before or during the interview. Difficulty in full anonymity of participants' details was considered as records were accessible to the researcher, study supervisors, and the study site coordinator. Furthermore, difficulty of complete confidentiality of data was considered, as direct quotes may be used from participants' responses. Codifying participants' names and removing identifiable data from ensured participants' anonymity.

Risks to the researcher were not experienced at any stage of the study, although this was possible due to lone working nature of data collection. A risk assessment and a study-specific lone working protocol were developed as a guidance for ensuring the researcher's safety. A lone working contact sheet was also designed to ensure that the details of the people to contact in an emergency were readily available. Possible risks were minimised during lone working by ensuring that a person from either the study supervisors or someone from the researcher's local workplace acted as the nominated person. The nominated person was contacted by the researcher before

and after each interview as stipulated in the protocol (see the risk assessment, lone working and lone working contact sheet in appendices 12, 13 and 14).

#### **4.9 Research rigour**

To ensure that my understanding and interpretation of participants' stories reflect their intended meaning, as a researcher, applying caution to transcription and the analysis of collected data was necessary. As a starting point, it was warranted that a clear understanding of the participants' mimetic positioning in given accounts was appreciated (Riessman, 2008). It was useful to understand that as in any narrative accounts, access to the narrator's lived experience is limited (Riessman, 2008).

Transcription of the collected data in this study was verbatim as this represented the narrators' perception of reality which was relevant to the specific instance of their conducted interview and reflected through the contents of our discussions.

The interpretation of collected data in a narrative inquiry is considered a product of the epistemology and ontology on which the endeavour was based (Riessman, 2008). The persuasiveness or trustworthiness of the findings may also be based on these (Riessman, 2008). Indeed, this may imply that the trustworthiness of the findings from a narrative endeavour relies on researcher's ability to defend the views presented in interpretations. While this premise may be true in some cases given the fluidity of participants' stories (Clandinin, 2013), it may however also suggest the concentration of more focus on the trustworthiness of presented findings rather than the process by which the findings are derived.

The strength of the findings of this study lies in the process of its conduct rather than the need for persuasion. Although trustworthiness of the transcripts remains a crucial part of consideration for rigor in a qualitative research (Poland, 1995), debates about the ontological and epistemological positions in narrative research also remain. Some of these consider the possibility of the interpretation being defined by the researcher's

underlying assumptions (Vasilachis de Gialdino, 2009). Others highlight bias in interpretation of findings as a possibility as a result (Bracken, 2010; Ratner, 2002). It is however also necessary to clarify that the meanings or interpretations of findings of a phenomenon may vary from one researcher to another (Scotland, 2012).

In similarity to the literature review, participants' narratives from the interviews in this study also varied. It was important to ensure that (a) the presentation was a true account of participants' narratives (b) the heading needed to fully capture the participants narratives from the interview. A key decision was also necessary to determine how these headings were derived and whether to present the analysis on a case-by case basis, or by theme. The iterative nature of the restorying process in Chapter 4 suggests that a thematic approach was more appropriate, whereby extracts from transcripts across the full range of participants may be represented using narrative headings as an illustration of the overall views being expressed. Five groups of narratives were derived in total as themes across the interviews during the analysis. These narratives, presented in the next chapter under the headings: control, loss, coping, role change and help-seeking, are similar to the findings of the literature review in Chapter 2. They also represent the focus of the findings chapter as a reflection across all the participants' accounts which in many ways may also be interlinked.

#### **4.10 Conclusion**

The research methods adopted have been discussed in this chapter and justified through the rationale for their selection. Some of the difficulties encountered during the data analysis stages, such as the uncertainty of a clear representation of collaborative co-construction have also been explored. It has been established that while restorying of participants' interviews may be crucial in making meaning from the narrative of their experiences, their stories are credible and necessary for the integrity

of their accounts in how these were analysed. The findings are presented in the next chapter.

## **Chapter 5: Findings**

### **5.1 Introduction**

The research question of this study was *“What are the narratives of care provision by family carers, and how do they describe their experience of home-based care for people with a moderate to advanced dementia towards the end of life?”* Three objectives were set at the beginning of the study, which placed emphasis on the participants’ own description of caregiving in order to understand whether their experiences included a description of internal conflicts, and how this may also be used in understanding the experience of moral distress. These were set as follows: (a) to identify whether, and how family carers describe internal conflict as part of their experience of end-of-life care provision; (b) to determine whether family carers’ description of internal conflict signifies the experience of moral distress, and (c) if present, to describe the narratives of caring that family carers have about internal conflicts leading to moral distress. In this Chapter, the findings from the analysis of the interview transcripts as previously described in Chapter 4 are presented by adopting a narrative approach using a thematic analytical process developed by Riessman (2008).

#### **5.1.1 Participants’ demographic information**

The participants, ten women and five men with a mean age of 67.93 years, were all interviewed within their domestic home setting. Interviews lasted between 60 and 75 minutes with a mean duration of 67.5 minutes. The recipients for whom care was provided at either the moderate or the advanced stages of dementia had a mean age of 80.6 years. All participants were white, with seven having been educated up to, or beyond undergraduate degree level. Most of the participants had provided a home-based care to the care recipients for a period between two and five years. Within the previous six months, three participants had also supported the care recipient in moving into a residential care facility. For these three participants, only past

experiences were given. Thus, only twelve of the fifteen participants were current carers. Further demographic details of participants are detailed in Table 5.1.

Table 5.1: Participants' demographics

<b>Participants' characteristics (n=15)</b>	<b>Category</b>	<b>Total</b>
Gender	Male	5
	Female	10
Age range	30-49	1
	50-64	4
	65+	10
Additional role outside of caregiving	Paid employment	4
	Unpaid or volunteering	1
	Volunteer	1
	Retired/others or unspecified	9
Relationship to care recipient	Adult-child	6
	Spouse	8
	Unmarried partner	1
Length of caring	≤ 1 year	3
	2 – 5 years	9
	> 5 years	3
Paying for additional care	Yes	7
	No	8
Dementia stage	Moderate	9
	Advanced	6
Types of dementia	Alzheimer's	4
	Frontotemporal Dementia (FTD)	1
	Mixed	2
	Parkinson's dementia	1

	Unspecified	4
	Vascular	3
Age of person with dementia	60-70	1
	71-80	6
	81+	8
Current place of care	Domestic home	12
	Care home	3

## 5.2 Presenting the narratives

Participants' responses during the interview show that their experiences were shaped within interactions as a social entity rather than within an existential vacuum (Baker, 2015). Some of these experiences, described in terms of their anxiety, frustration, anger, powerlessness, hopelessness, isolation, personal accomplishments, and uncertainty, were already established hallmarks of internal conflicts and moral distress (Milne, 2018; Fumis et al., 2017; Borhani et al., 2014). Five groups of narratives are presented in this chapter under the headings: control, loss, coping, role change and help-seeking. These narratives derived as themes across the participants' interviews during analysis, are useful for exploring given accounts and how these were experienced.

The participants' description of how these experiences were internalised differed between narratives. Some were influenced by the care recipient's illness progression, while others were due to the existence of a relationship between the participant and the care recipient. Overall, the wish for a sustained home-based caregiving despite the care recipient's decline and a reliance on, or a desire to seek for help as the illness progressed were both common perceptions. The findings are presented across the five narratives using individual participant's stories as an illustration of the collective experiences found during the analysis. A combination of the participants'

initials and the numerical order in which they were interviewed were used for their anonymity. The narratives were presented in no particular order, but in each of these narratives, participants' direct quotes were *italicised* and enclosed in double quotes for clarity. The overall representation of the findings across all narratives is shown in Fig 5.1.

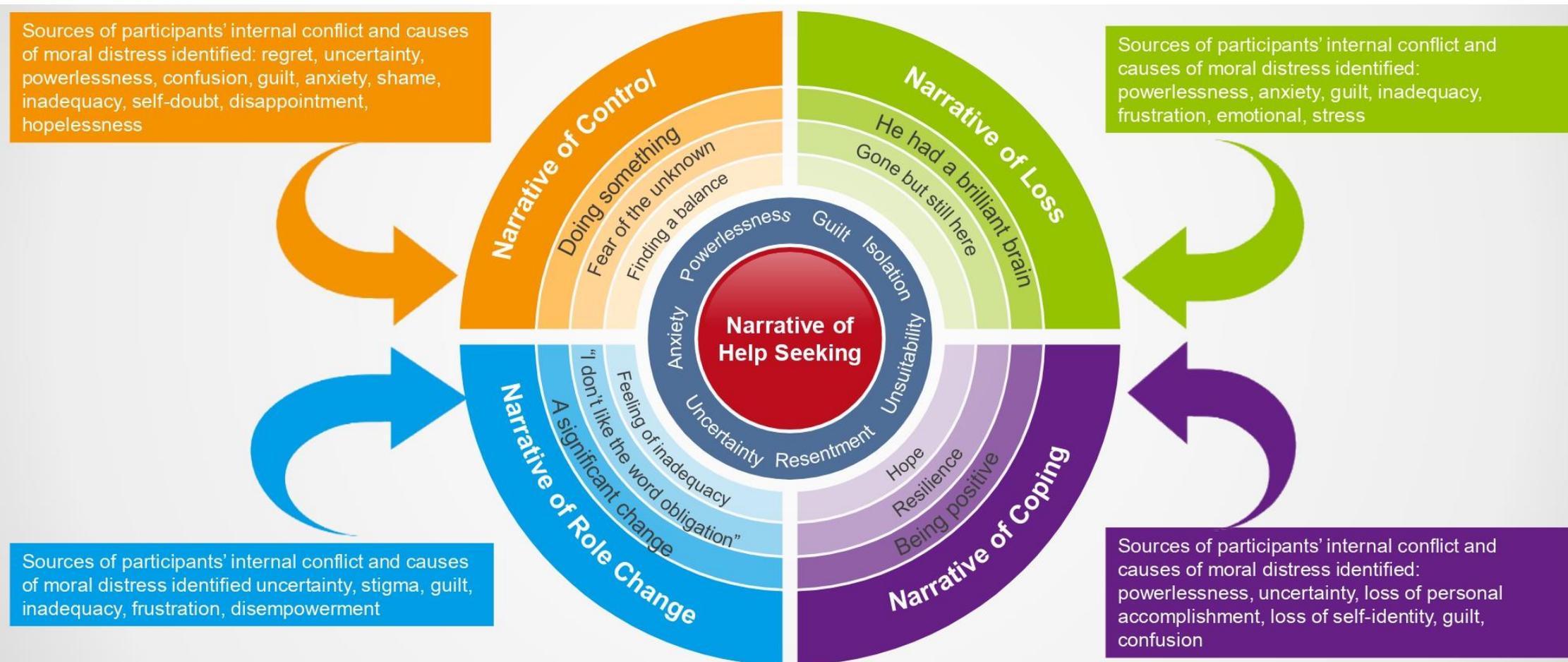


Fig 5.1: Family carers' experience of home-based caregiving for people with moderate to advanced dementia towards the end of life

### 5.3 Narrative of role change

Participants struggled to make sense of their suspicion of an illness prior to and following a diagnosis of dementia. Looking after someone seemed a natural thing to do for some of them. However, the consideration of the caregiving role as an obligation was contentious as this did not fit the participants' own perception. These findings are illustrated in the following stories by P2, K1 and S1.

#### 5.3.1 A significant change

##### *The story of P2*

P2 was concerned about her husband's forgetfulness prior to being diagnosed with Frontotemporal dementia (FTD). His forgetfulness was considered out of character as he had "*...never had a man's cold in his life...*" Some of the post-diagnosis changes were regarded as dis-inhibitions and reflected by a limited ability to function as he once did. These were attributed to dementia and regarded as quite significant as they represented a change in everything "*...that's when somebody has dementia...it affects everything...*".

A role transformation was experienced based on the perception of behavioural changes. This was viewed as an instinctive necessity based on the existing relationship and co-habitation: "*... he reverted back and...it's instinctive if somebody can't do something, you love them and you live with them, you do it for them.*" P2 was unable to clearly state the point at which a transformation occurred. She however perceived this as a gradual process "*...gradually you became aware...*"

The care recipient's post-diagnosis behavioural changes had a negative impact on social structures. P2 described this structure as such that emphasise conformity to social expectations. Following the diagnosis however, her husband developed a dis-inhibition with food which "*...became awkward, it looked like greed*". She suggests that the deviation from this structure which was a result of her husband's behaviour

was inconceivable: “...*In our social structure, children are brought up...So, by the time they are five, socially, they have to conform...*” P2 felt that this deviation may cause people to see her husband ‘in a different light’. This may also suggest a reference to unintentional stigmatisation and a possible cause for role transformation “...*It becomes embarrassing...and people see [mentions husband’s name] in a different light...*”.

### **5.3.2 “I don’t like the word obligation”**

#### ***The story of K1***

Caregiving for her partner upon their return to the UK was described as a natural thing to do after his diagnosis of mixed Alzheimer’s and vascular dementia, as it was quite manageable “...*just natural to sort of look after him...*” K1 and her partner were living overseas when he became “...*quite forgetful...misplacing things...*” Their return to the UK was necessitated as a result of the language barrier in accessing medical assistance. She did not worry too much about it until his family became concerned due to his gradual decline. She however considered caregiving for him as a reciprocal endeavour as he had previously looked after her during a serious accident.

Distress was felt given the perception of self-sufficiency as an attribute of caregiving. As a distinctive illustration of an internalised conflict, K1 questioned her decision-making “...*Am I doing the right thing?*” There was a reluctance in asking for family assistance as she considered that having lived a good life, not caring for him was inconsiderable “... *the natural thing to do...what else would I be doing now?*” This was however not perceived as fulfilling an obligation, but as a resolution of a commitment in an existing relationship “...*I don’t like the word obligation...It’s an obligation if I’ve got to do it... it’s a fact that we have been together for 20 years...*”.

A sense of guilt was also experienced in association with the progressive decline and the increased level of care needs. K1 explained that she has arthritis and other mobility issues, which made caring difficult. She needed a break from time to time from caregiving and sought help from social services. Their suggestion of a residential respite for her partner however had a negative effect on her *“...it makes me feel really guilty and horrible”*. She felt this was a betrayal *“...I am betraying him...”*, and considered that he would feel she was sending him away *“...he is going to think I am getting rid of him.”*

### **5.3.3 Feeling of inadequacy**

#### ***The story of S1***

S1 was trained as a nurse and had previously worked for 40 years before taking on a non-caring role within a local care home. She described herself as someone with a strong conviction for care provision, and an ability to recognise vulnerability in people who require care *“...I recognise their vulnerability and I had a great affinity with them quite quickly....”* This recognition of vulnerability, which was attributed to her previous emotional abuse, was also pertinent in her description of empathy and engagement in caring *“...I can recognise quite quickly when they are feeling fragile or scared...”* Her perception of affinity, however, appeared to describe a recognition of love or affection *“...there was no love, there was no... there wasn't that affinity with me with her...”*.

S1 had difficulty in making decisions regarding her father's care needs following his diagnosis of Alzheimer's *“...I don't always feel confident in making a decision...”* Making decisions about him was an affection-based function, which made it more difficult than caring for anyone else *“...it is more difficult because it's my dad...”* The view of her father's vulnerability was not held, possibly due to her perception of his resilience through a lifetime of hard work *“... he's been very busy since he was*

*12...10...12 years old, never stopped...I think dementia had already started...*

Instead, an acknowledgement was made of a dissociation between this pre and post diagnosis identity *"...now he's not the dad that I had..."*.

Dissociation was a source of conflict between professional competence and capability as a daughter. This perception, which may suggest that a feeling of inadequacy was also experienced, highlighted a frustration in making decisions regarding her father's care *"... I feel a bit umm... vexed ... I don't feel I read it correctly all the time from whatever nurse point of view or a daughter's point of view..."* A fear of possible disempowerment was therefore held as she felt she might be taking over too many things that he was previously capable of doing by himself *"...I am taking too much from him."* She expressed her sadness about his post-diagnosis self, which she believed was responsible for his incapability *"...sad for my dad really that ...his body is failing him and now his mind is failing him..."*.

## **5.4 Narrative of control**

An expectation to 'do something' about the care recipient's condition appeared to be a common perception in participants' ability to make meaning of the caregiver's role. Their descriptions of anxiety and hopelessness as shown in the stories of A1, D2 and B2 appeared to be hallmarks of a fear of the unknown and the need to find a balance.

### **5.4.1 Doing something**

#### ***The story of A1***

A1 expressed a regret at his wife's diagnosis of dementia following *"...a few problems with memory loss..."* He referred to her diagnosis as a terrible weight and considered finding out the worst time of his experiences so far, *"...of the whole experiences so far, that was the very worst time when she was first diagnosed"*. Distress was experienced by the disclosure of the diagnosis *"...we were in tears almost every day*

*the pair of us...,” and he wished that a diagnosis had not been disclosed “... in hindsight, we, I wouldn’t have said yes...”.*

Prior to her diagnosis, they had planned to take a holiday together following his retirement. A change in life’s course was however necessitated by the diagnosis, which he described as “...a kick in the nuts...” Her progressive decline was viewed as happening “...in slow time...”, while the process of caregiving represented a gradual transformation: “...it’s something that grows on ya...” As such, an unwillingness in finding out the course of the illness progression was necessary by adopting what he termed a “...head in the sand view...” He did not consider this ‘an inaction’ or ‘giving up’, but as a way of making meaning of the illness and possibly in conveyance of his fear of doing the wrong thing. Although the negative impact of obtaining a diagnosis was reported, a belief that it was the right thing to do was still held “...I would have felt worse, yeah. I did what was right for me...” The declaration of his preference to allow the illness to take its course, “...let them happen...” may therefore signify that a feeling of powerlessness was also experienced.

‘Doing something’ or acting was a natural instinct. A1 described himself as someone with a general approach to solving problems, which may be as a result of his previous professional status: “...if there is a problem, I’d do something about it...” However, understanding the appropriate timing for acting in dementia was a source of an internalised conflict. He clarified that although he had concerns about his wife’s memory loss, a formal diagnosis was delayed for up to two years as the severity of it was unknown: “...wouldn’t have put her in for this if we didn’t think something was wrong...” Following her diagnosis, it also appeared that a confusion in understanding the extent of progression persisted “...that’s a job to tell...is she getting better? Or worse?... it’s very difficult...and after three or four months, you think she’s not really any worse than she was before...”.

## 5.4.2 Fear of the unknown

### *The story of D2*

D2 was a caregiver for both her parents but assumed a sole caring role for her mother since the father passed away. She described caregiving for her mother who has a diagnosis of Alzheimer's as being "...on a hamster wheel and you just have to keep going..." She acknowledged a difficulty in getting support in looking after her at home and her own reluctance at relinquishing care to strangers. The constancy of her caregiving responsibilities caused her family to become concerned for her health. A progressive decline in her mother's illness however caused an anxiety such that D2 felt that she was unable to continue within her caregiving role "...I knew I wasn't able to carry on like this..." A placement in a residential care home was therefore necessary.

Before a residential placement decision was taken, D2 regularly visited her mother at home. Her mother was still capable of some level of self-care, but this deteriorated progressively. D2 described her constant anticipation of '*what may happen next*' as a cause of fear. She described her mother's actions as progressively worsening to point where "...she was inappropriately eating ...wasn't looking after herself personally umm... very well...".

D2 perceived a need for control over the situation when her mother took an overdose. She expressed a disappointment and her desperation when told by her GP that "...there's nothing I can do..." She also expressed a feeling of shame at putting her mother permanently in a care home following a social worker's advice against respite "...the social worker said don't do respite... they find it very difficult to go back...".

Perception of an inability to fulfil her responsibility was equivalent to breaking a promise, and a source of powerlessness. She stated that while her father was ill, he "...begged me, please don't send me into a home... and I didn't." This was also

associated with her feeling of guilt “...I just feel guilty because I can't keep her, I can't look after her at home...” She felt that she had failed her mother as an equivalent care which allowed for this promise to be kept was impossible “...I felt in some ways I should be doing that for mum as well...”

A feeling of guilt was also expressed as D2 felt judged by other people for her actions. She attempted to understand this feeling by expressing her perception of the nature of dementia as “...not an illness that is easy to see...” She concluded that it was easier for people to think that she did not care, “...they probably think...I haven't looked after her and I've, you know put in a home because I can't be bothered or whatever and that's not the case...”.

### **5.4.3 Finding a balance**

#### ***The story of B2***

Prior to her mum's diagnosis of Alzheimer's, B2 also looked after her dad until his death three years previously. She described how having a close relationship with her mum was a possible reason for her mum's subsequent refusal of help from a paid carer following her diagnosis. B2's wish for good care for her mum was described as a compelling factor for accepting the role as the caregiver to the detriment of her own health: “...I want to do it for her because I want her to be happy and well fed...my health suffers and my fitness...”.

Finding a balance between caregiving for her mum and other competing responsibilities was a difficult endeavour. B2 divided her time between caregiving for mother and spending time with her terminally ill husband. Describing this as a dilemma and citing time as a factor in her caregiving role, a perception of inadequacy and powerlessness was also held. B2 described this as: “...always dividing my time between the two and dashing from one place to the other, never feeling as if I do anything completely well to the best of my ability.”

Guilt was expressed following a decision for her mum's move into a residential care home in order to allow some time with her husband and for safety reasons. She described an internalised conflict as balancing her reluctance at placing her mum in the care home, "... *I really didn't want to have to do that but...*" and spending time with her husband "...*my husband is probably only at best got a year left...*" B2 also expressed guilt at going against what she perceived as her mum's wishes "... *I do feel incredibly guilty about thinking about moving her into a home as I know it's not what she wants...*" A justification of her plan was given as a consideration of what her mum would have wanted pre-dementia. While this may be an attempt at understanding her reasons for feeling guilt, she concluded that the situation was hopeless given her mum's present state of mind: "...*I'm sure pre-dementia if I could reason with her...I'm sure she would understand...*".

## **5.5 Narrative of Loss**

The description of loss as a gradual decline of personal attributes was common. As illustrated by the stories of J1 and B1 below, the gradual absence of these attributes further explains participants' common perception of loss as a consequence of the illness progression.

### **5.5.1 "He had a brilliant brain"**

#### ***The story of J1***

Following his recovery from a heart attack, J1 husband's forgetfulness was a concern for her. A need for a covert medical opinion was necessary so as not to cause an undue upset. The realisation of his problems was both a source of sadness and a relief once diagnosed with Alzheimer's. Relief was expressed at being given a diagnosis, "*Relief really, that we knew what the problem was...*" A reluctant acceptance of the condition was also highlighted, which may signify that

powerlessness at changing the diagnosis was also felt: “... *we just have to accept it...*”.

J1 described her husband’s brain as his defining attribute. The notable absence of its full functionality was therefore perceived as a loss of his defining characteristic: “...*he had a brilliant brain... those that know him from childhood think how sad it is he is as he is.*” Being exceptionally bright was also perceived as a family attribute “...*we’ve got quite a reputation going...you know what sort of brain he has.*” As such, the loss of her husband’s defining characteristic required a personal means for coping, which was offered by the diagnosis: “...*we then knew what the problem was...and ... how I could cope with it.*”

J1 understood that her husband’s reliance on her would increase with the illness progression, but powerlessness was felt at stopping his decline: “...*I knew that they don’t get better, they gradually get worse... he would get more reliant on me.*”

Although the loss of his defining characteristics was progressive, she was resolute in her decision not to send him into a care home permanently, which was identified as an internalised conflict between her guilt and the feeling of relief: “...*at the moment, I don’t want him to go in the care permanently... no, it has to be a lot worse...*”.

This conflict also remained unresolved as although a non-recognition of her presence was often endured due to his progressive decline, “...*sometimes now he doesn’t know who I am...*” caregiving was perceived as a progression of marriage vows “...*I just naturally took the job on...It was sort of a natural progression as a wife...*” While being in permanent care would mean that she has a bit of time to herself, it would also be an admission of her inadequacy to look after him: “...*half of me would feel relieved but half of me would be guilty that I couldn’t look after him sort of thing. It’s a difficult one that one.*”

## 5.5.2 Gone but still here

### *The story of B1*

As a naturally sociable, B1 described a feeling of an increasing isolation following her husband's decline due to a diagnosis of Parkinson's dementia. Being able to socialise became increasingly difficult "... *I just can't go out and socialise anymore...*" although the need for social interaction remained crucial: "...*to talk about something different other than caring and dementia.*" The feeling of anxiety due to the changes associated with her husband's progressive decline impacted on her ability to consistently use her local gym "...*if he's having a bad day, I won't go anywhere...*" She perceived her caregiving experience as being both emotional and frustrating.

The loss of cognition was described as "...*weird*" due to a lack of knowledge of dementia prior to her husband's diagnosis: "...*I had never met anyone with dementia so it's all new to me...*" The dementia-related changes exhibited by his illness progression were unexpected, and her inability to associate his loss of cognition with the decline was a result of this lack of prior knowledge: "...*I thought it was just I can't remember your name or general things. It didn't occur to me it was cognition as well.*" An increased level of stress and anxiety was experienced by B1 due to the loss of cognition, which included his inability to recognise basic items, and engaging in dangerous activities "...*he doesn't even recognise trousers... He's doing dangerous things now.*"

B1's distress was shown at expressing this experience and resulted in a feeling of powerlessness at changing the situation: "*He's not really there anymore. That's horrible to see that when someone isn't... when they've gone... I don't know where they are [participant sobs].*" This feeling of powerlessness also highlights a dissociation from her moral marital obligations "...*just part of being married to someone...you just want to help them...it makes you feel useless...*" This loss of

cognition was therefore equivalent to total loss as B1 felt her husband had already died, although he was still alive.

A possible conflict between loss of cognition and a resolution for continuation of caregiving at home leads to a feeling of guilt. B1 explained her husband's loss of cognition is inclusive of an increasing level of violence: *"...this morning I thought he was going to break my finger."* While a wish to keep him at home was expressed, the need for caregiving safely was also identified *"...don't want him to go in to care... but I know if the violence continues and gets worse and worse that one day, I'll have difficulty controlling it... but I won't have any choice."* She considered this too distressing to discuss further.

## **5.6 Narrative of help-seeking**

Progressive decline necessitates the need to seek for help. Challenges are faced as the process for seeking help was difficult. The wish to keep the person with dementia at home was, however, prevalent. Although the perception of caregiving as a duty remains, the difficulty in meeting the recipients' needs represents a conflict between doing the right thing and fulfilling pre-dementia promises. These findings are further illustrated in the following stories by P1 and S2.

### **5.6.1 "It was my duty"**

#### ***The story of P1***

The marital vow between P1 and his wife was a compelling agreement to look after her once diagnosed with Alzheimer's. As a moral necessity, he considered this a duty: *"... you get married...in illness and in health... and it was my duty as her husband to look after her...that is what I did for seven years..."* Rapid decline due to the illness however meant that a self-denial of once enjoyed activities was necessary: *"...I had to pack up playing golf cos I couldn't go out."* The illness progression also

meant that a need for seeking external help was necessary, which he described as a challenging: *“... she gradually got worse... it was uphill battle to get something done for my wife.”*

The process for obtaining help caused uncertainty and anxiety. P1 expressed disappointment in the unsuitability of the help offered by social services, given the level of decline and constancy of care: *“So I said...what are you talking about? Half an hour a day?... I’m getting no sleep for two weeks...”* The advice of getting her into a care home by the social services was also disappointing and a source of an internalised conflict as P1 wanted to continue caregiving at home: *“I would not have considered a care home. I wanted to keep her at home here, with some help.”* Some of the care homes recommended were too expensive while others were inappropriate given their restrictions: *“...I don’t wanna go in there because I’ve seen that it’s like a prison.”* His wife’s eventual placement in a care home was an unresolved conflict as he did not think she was ill enough, though her cognitive decline was acknowledged: *“...it is a bit of a shock you know, I realised she was poorly, but I didn’t think she was that poorly...”*

P1 reported a feeling of guilt about his wife being in a care home. Perceiving this guilt was a possible admission of not doing his best *“...I don’t wanna feel guilty that I haven’t done my best for my wife...”*, he regarded his daily visits as a part of an enduring agreement to care, and a motivating factor for continuing his duty to care at her present place of care. He was however resentful about the restrictions placed on his involvement as an outsider in her present care *“...the rules and whatever it is, there’s so many of them...you try to conform to the rules if you can, to make it easy.”* He also felt powerless against these rules which were a hindrance to his ability to fulfil his duty: *“...I’m disappointed this is about all these rules really, because I feel like I’m trying to do my best, and I’m trying to keep my wife as long alive as much as*

*possible.*” Converse to the powerlessness previously experienced at performing his moral duty at home however, continuing with his daily visits was justified in allaying the guilt felt at her care home placement: “...*I don’t want her to feel that I’ve just dumped her there and forget about her. So, I go there every day... I would feel guilty if I didn’t go.*”

## **5.6.2 Getting help is difficult**

### ***The story of S2***

S2 perceived his caregiving experience of looking after his wife with dementia in the advanced stage as being “...*a bit like a hamster...going round on a treadmill.*” He expressed her decline and a struggle to adjust to the speed as the biggest challenge of this experience, as she became fully dependent on him for everything within a short space of time. This had negative consequences on his ability to care for her at home: “...*the speed of the decline has been the biggest challenge ...so the consequences for me are that I am trying to care for her at home, but it is getting increasingly more difficult...*” S2 portrayed himself as a confident man who felt powerless to change his situation as a result “...*I can’t make anything happen here on this one-way path...*”.

S2 experienced a feeling of uncertainty in understanding the type of help required following his wife’s diagnosis and her rapid decline: “...*you have no idea at the time what help you are going to need...*” The rapidity of her decline meant that an expectation of a manageable illness progression was unmet and possibly a source of an internalised conflict: “...*I had an expectation that after diagnosis there was several years of decline, my head said 7 or 8 years... it’s still not 2 years since diagnosis...*” This conflict was unresolved as a feeling of abandonment was also experienced. S2 expected support in his new role as part of a process of illness management after a diagnosis of dementia. He expressed this as an unmet need and as a

disappointment: "...nobody is overseeing your case continuously ... that doesn't exist."

Difficulty in getting help appropriate to the level of decline led to a feeling of guilt: "...I have had situations where I have had to turn down appointments because I have had no way of getting a carer..." He perceived getting professional support difficult and an unwelcoming process for people with a diagnosis and their caregivers: "I don't know any carer who can point to a trail of support...you get on a caseload of somebody and because of the demand, they want you off the case load and so the first thing they want to do is sign you off..." Indeed, he had relied on family and friends in the past. He considered this form of help inappropriate to his needs: "...they can't cover every situation..." Similarly, help from friends and neighbours was regarded as a selective type of help to be sought only as a last resort: "...you want them to help you on the most critical times...".

S2 viewed his wife's possible placement in a care home as an admission of being a failure "...you feel you should be able to look after your wife at home and if you don't or can't and you go to a care home, it feels like you have failed as a carer..." The possibility of his non-involvement in her caregiving as a result was therefore regarded a dereliction of his duty: "...you vowed to look after one another all your life... a dereliction of duty kind of thing, and makes me feel guilty that I don't spend all my time devoted to her." He identified this as a source of his guilt "...it's going to make me feel guilty, going to make me feel that I haven't been doing a good job, that I can't do a good job, inadequate..." However, powerlessness over this prospect of care home placement was also felt "...I haven't had to experience that yet, but I know it is coming...".

## 5.7 Narrative of Coping

The conflict between doing the right thing and fulfilling pre-dementia promises, and the participants' acknowledgement of a powerlessness to effect changes in the deterioration process empowered them to devise several means of coping. A fear of the recipient's loss of autonomy was common but most of the participants highlighted the need for resilience, hope and being positive as in E1, J2 and M1's stories.

### 5.7.1 Being positive

#### *The story of E1*

E1 described his father's decline following a diagnosis of mixed Alzheimer's and vascular dementia as being a "...*gradual slow decline...*" Compared to the family expectation, he considered this a relief as caregiving at home was still possible: "...*it's like 6 years since his diagnosis and you know he's still at home...*" Although the only child, his parents had initially resisted moving closer to him for assistance with care duties until when his mum started struggling to cope. He also felt that getting diagnosed relatively early was good so his father could "...*get the help and support they needed...to help slow the progress...*".

Describing his father's diagnosis as also "...*fairly worrying...*," he highlighted a disparity in service availability across the country and expressed moving them closer as a good thing "...*they seem to be getting more help in this area than they were...where they lived before...*" He considered this disparity as being unique to people with dementia: "...*there's a bit of variation across the country in services and enthusiasm for supporting people with these kinds of issues.*" A worry about the future and the uncertainty of the diagnosis remained as a result. He explained this as an uncertainty regarding future problems in relation to his decline and how long they would be able to manage his care at home.

E1 expressed a fear of his father losing his voice in his care considerations. He considered that although his decline necessitated a change in collective behaviour, there was still a necessity for him to remain independent. He described this as a need to maintain his autonomy for as long as possible considering that he is *"...not just a diagnosis. He's still a person."* Staying positive and being truthful with him was therefore adopted as a selective mechanism for coping with the decline. E1 was careful to distinguish between the selectivity of this approach as a choice and not a denial of the illness. His explanation portrayed being positive as a choice: *"...try to stay positive and not be in denial about it, not kind of pretend it's not happening, stayed really honest with him..."* This also appeared to have suited both the caregiver and the care recipient: *"...he kind of joked about it, blamed it on Alzheimer's ..."*.

## **5.7.2 Resilience**

### **The Story of J2**

Until her formal diagnosis of vascular dementia, J2 had not realised her mother was ill. She described her family as naturally resilient. They do not talk about medical problems between them: *"...if we hurt, we hurt...we don't talk about it...we don't do illness..."* J2 explained that she has a familial history of dementia. She was apprehensive that she too might develop the disease. However, she appeared to have developed a positive attitude, which may be attributed to her family's approach to dealing with illnesses *"...I'm looking forward to it...presumable it will pass to me..."* This assumption was based on her forgetfulness, especially of people's names. She however also expressed hope and related her forgetfulness to her age *"...things like that happen as you get older..."* She considered herself as having adopted the resilient way of life *"...I just sort of brush it off and deal with what's happening at the time. If there is something tangible, I can deal with, I will deal with it..."*.

As an unmarried adult-child caregiver, J2 had taken up caring for her mother after retirement. Her sister had died previously and she “...*sort of just took over, looking after mum...it was something you do...*” From her understanding, a carer occupies a space of acting on behalf of the cared for given that “...*they do everything...*” for the person being looked after. Her mother was still capable of a considerable level of self-care, and as such, she considered herself “...*a daughter...*” rather than a carer. In understanding her role as a natural undertaking, a respect for her mother’s autonomy in decision making was also highlighted. This appeared influential in J2’s unwillingness to consider putting her mother in a care home even if caregiving became challenging: “...*she wouldn’t want to go in a home, even if it got too much for me...I would have to move in with her...*”.

J2 experienced a dichotomous sense of loss which appeared to be a result of her consideration for the care recipient’s autonomy. The first appeared related to the loss of personal dreams. J2 had planned to move into a cottage following her retirement “...*I haven’t gone because of mum...*” The second type of loss experienced appeared to describe a loss of self-identity. As a widely travelled professional, this loss was gradual and resulted from an increasing level of dependence “...*slowly, the world started to go inwards a little bit, between here and 200 yards down the road.*”

A feeling of powerlessness to influence a change in attitude of the care recipient was also expressed. The progressive decline meant that activities once jointly enjoyed were no longer possible due to the care recipient disinterest: “*She won’t come with me and she won’t go anywhere with me...*” Although she considered this restricting: “...*the world has become a much smaller place...*,” her wish for her mum to be happy and not “...*feel like she is a burden...*” was also pertinent.

J2 did not find her caregiving role challenging. The feeling of guilt that she had carried since losing her sister however appeared to have an influence on how a

balance is achieved. She considered her inability to spend more time with her sister before she died as a failure *“Had I have taken that month off I would have been with her and I’ve felt guilty ever since...”* She therefore described her approach as *“...see things that need doing and trying to do them...fit them into a timescale and my things tend to get waylaid...”* Due to the guilt and a fear of the unknown, personal needs are therefore sacrificed *“...I don’t want the same thing to happen to mum.”*

### **5.7.3 Hope**

#### ***The story of M1***

M1 was conflicted with coming to terms with her husband’s illness following his diagnosis of vascular dementia. Prior to his diagnosis, M1 stated that he had been a fit man, and was never ill: *“They did all the tests on him in the hospital... there’s nothing wrong with him... he’s been a fit man. I’ve never known him ill in his life before.”* M1 felt depressed by his diagnosis and expressed her loss of independence due to his isolation. Confusion and internalised conflict were also experienced with his diagnosis as she considered that her husband had been *“...quite irritable at times, but then he always has been...”* She did not think he was ill enough to justify the length of his admission in hospital: *“...he was there for 16 days, not because he needed to be...”* She however felt there was a need to accept the condition: *“...you just have to come to terms with it...”*, which was a resolution based on her feeling of a powerlessness in changing the situation, given the progressive nature of the illness *“...they don’t go up ever, they go down in steps...”*.

Dementia was not considered terminal, but as an illness with no cure *“...there is no cure for this at the moment...”* This perception was held by making a comparison with cancer, which M1 regarded as being terminal *“...even cancer, I know that’s terminal...”* Vascular dementia on the other hand was perceived as *“...all to do with...blood flow to the brain...”* As such, hope of a cure being found was held on to

*“...there must be a cure for that if there’s a cure for cancer.”* There was however a dichotomy between holding on to hope for a vascular dementia cure and her previous experience of witnessing patients in her local hospital being *“...kept artificially alive. They keep giving them medication...”* This dichotomy appeared to exist between her understanding of there being no cure for dementia *“... those with dementia, they’re not gonna get any better...”*, and her objection to life being preserved at all cost. Referring to this as *“...the Hippocratic Oath...”*, explained as the medical profession’s conviction of preserving life at all cost, she also believed that people *“people should be allowed to die naturally...”*.

## **5.8 Interpreting across narratives**

Participants who took part in this study were all family members of the care recipient. Being all white, mostly aged over 60 and from the Eastern region of the UK, they shared a similar demography (see section 5.1.1). They all remained involved in recipient’s caregiving, though three of them had already made a transition of recently placing the care recipient in a residential care home. Their narratives were interlinked by a characteristic plasticity, an evidence that their moral distress was possibly moulded by their internalised conflicts encountered in caregiving. Their common preference to keep the recipient at home may however be unrelated to the commonality of their demography.

All participants experienced loss as a consequence of illness progression. The findings establish the coherence of a combined description of loss as a gradual erosion of the recipient’s identity or a valued participant-perceived attribute as the disease progressed. This process was perceived incomplete until cognition is totally diminished, which acknowledges a finality in existence, and a powerlessness to alter the course of illness progression. The recipient’s description as ‘gone’, while still alive, gives an indication that this powerlessness may have been due to an

internalised conflict or personal struggle in attempting to understand or accept the illness and its progression.

Participants shared a common struggle in making sense of their situation and an uncertainty of what to do following the diagnosis of dementia in the recipient. The findings show that a role transformation was necessitated due to this experience, as a complete shift from a pre-diagnosis relationship with the recipient to a post-diagnosis alliance. Commonality of a difficulty in understanding the exact point at which a role transformation occurred was also found. While the reason for this difficulty may be explained by the unpredictability of the decline, a need for the preservation of the care recipient's personhood, or a participant-perceived value of the care recipient was found to be an important determinant of its timeline.

Participants also demonstrated that caregiving responsibilities increased progressively with the decline. In spite of the decline however, participants' transformation remained stable through the illness trajectory. As an interplay with the motivations for sustaining caregiving, the existence of a pre-diagnosis relationship between the participant and the recipient was a crucial factor.

The meaning attributed to role transformation is established as a necessity and not as an obligation. Also described as a natural undertaking, caregiving as part of the role transformation was further perceived as a duty. These descriptions give the importance of value placement on the pre-diagnosis relationship between the participant and the care recipient as shown in the findings. This variation of perceptions however raises a question of understanding when performing a duty becomes a fulfilment of an obligation. This knowledge is pertinent in differentiating between the participants' choice and willingness to also give required care in the absence of an existing pre-diagnosis relationship with the care recipient.

It is clear from the findings that the experience of progressive decline, described as post-diagnosis behavioural changes, was common to all participants. How the behavioural changes were exhibited by each care recipient varied widely. While the participants' uncertainty in knowing what to do was common, a desire to make a meaning of their role transformation was also commonly demonstrated by a natural expectation to act. This may suggest an association between the existing pre-diagnosis relationship and an expectation for acting or 'doing something'. A reluctance to act prior to a noticeable decline shown by the findings also suggests that the timing for acting or 'doing something' was predicated on the participants' perception of the extent of decline.

The findings show that the uncertainty of recipient's decline caused a constant fear of the unknown. While there was a need for control over this fear, described as the *'anticipation of what may happen next'*, ascertaining the appropriate timing for acting or 'doing something' is difficult as the extent of decline is uncertain, given the progressive nature of the illness. However, similarities between the approach to acting or 'doing something' in caring for someone with dementia and approaches previously taken in engaging with other responsibilities emerged. For some participants, this was necessary in overcoming a reluctance to act, and for others, in reaction to a feeling of guilt.

The findings show that acting or 'doing something' as a means of having control can lead to a feeling of guilt within a social context. Participants' consideration of both the likely pre-dementia opinion of the recipient and the feeling of being judged by others were factors that caused guilt over the course of action taken. This may also suggest that participants felt an internalised conflict over the unknown probability of success in the decision taken. An unresolved guilt evidenced by the findings in the placement of the recipient in a residential care home is therefore possible.

The wish to keep the recipient at home was common. The findings suggest that placement elsewhere was associated with a diminished involvement in caregiving, and a perception of inadequacy, as well as an unfulfilled duty. The findings also demonstrate that there is an instinct to seek for help as decline progresses, in order to keep the recipient at home. This finding was however unaligned with the description of self-sufficiency as an attribute of caregiving. As an increasing level of decline was also reported, this possibly supports the evidence of powerlessness in participants' ability to fulfil their responsibility.

Getting help was difficult, and the process for seeking help caused uncertainty and anxiety. The findings suggest that guilt was experienced given the unsuitability of the help received to the level of decline. This perception supports the participants' fear of the recipient's loss of autonomy, which suggests that the perception of an erosion of independence was also held. In some cases where the decision for placement in residential care was agreed, this represented an internalised conflict for the participants as care at home was preferable in performing a moral duty. Where the performance of a moral duty is impossible, as shown in the findings, the feeling of being a failure is also an evidence of powerlessness. Hence, the experience of an outsider phenomenon due to restrictions on continued involvement in recipient's caregiving once placed outside of the domestic home was therefore possible as demonstrated in the findings.

## **5.9 Reflexivity**

My professional role within the domiciliary sector in the UK involves frequent conversations with families of people with dementia, who sometimes provide care within the domestic home setting. Bryman and Cassell (2006) highlight the possibility of the researcher being compromised by their own pre-existing assumptions during data collection. As this may influence how the data was interpreted, reflecting on my

own practices was necessary to maintain the integrity of the study (Bryman & Cassell, 2006). A methodical, self-conscious, and sensitive approach was therefore taken to ensure transparency in the conduct of the study. A diary was kept in which decisions made during the research process were recorded. These included reflections on personal experiences of caring for someone with dementia which occurred as part of my professional role. As a co-constructor of the narrative, dissociation from pre-conceived assumptions was further possible by focusing on the narrators' stories (Riessman, 2008).

The eagerness to make sense of the data meant that the possibility of a researcher-bias was high. This was especially pertinent given my familiarity with family carers' input within dementia homecare. Catanzaro (1988) highlight that the misinterpretation of participants' data may occur given the familiarity created during data collection in a narrative inquiry. Caution is therefore advised that the interpretation of the results must not be influenced by the researcher's perception of the phenomenon being investigated (Patton, 2002; Silverman, 2001). A plan was therefore developed as a result, such that analysis was undertaken after all interviews were completed and transcribed to minimise potential researcher confirmation bias. In Olken's (2015) view, this may encourage transparency of the analytical process so replication of the methodology would be possible in future research.

The interpretative nature of the narrative technique adopted suggests the necessity of presenting the narrator's stories as if "*full blown from the narrators*" (Riessman, 2008, p.3). Although, Riessman (2008) also suggest that post-transcription comments from the participants may be useful for the purpose of accuracy of collected stories, these were not sought given the sensitivity of the changing caregiving situation, especially the long duration of caring (von Känel et al., 2019; Tremont, 2011). Instead, verbatim transcription of collected data, including the narrators' hesitations, false starts and pauses between sentences was undertaken by myself as the researcher. A high level

of caution was also ensured by managing the transcribed data for analysis purposes with NVivo. Therefore, only the narrators' verbatim words were used as quotes in analysed data as well as in post-analysis interpretation.

## **5.10 Conclusion**

The individual stories of participants who took part in this study have been presented in their own words. Presenting their stories under the five narrative headings of loss, control, role change, help-seeking and coping gives structure to the context of the findings from their stories. An interpretation of their combined narratives has also been presented, which gives evidence of a characteristic plasticity of their experience of moral distress as possibly moulded by the internalised conflicts encountered in caregiving. These concepts which represent the participants' overall experience of home-based caregiving for someone with a moderate to advanced dementia towards the end of life are further discussed in the next chapter.

## Chapter 6: Discussion

### 6.1 Introduction

The purpose of this study was to explore how family carers describe their experience of home-based caregiving for someone with a moderate to advanced dementia towards the end of life. Evidence demonstrated that while the general experience of caring by paid carer groups such as nurses was widely explored, in-depth accounts of home-based caregiving by family carers for moderate to advanced dementia was limited. Within the literature review in Chapter 2, it was found that for the caregiver, loss and value were personified attributes of the care giving experience.

In Chapter 5, five narratives were presented by following a narrative thematic analysis guideline by Riessman (2008) on the interviews conducted with 15 study participants. The findings and their interpretations across narratives at the end of the chapter offer new understandings and knowledge creation through further enquiry within existing literature (Anderson, 2010). The research question is contextualised in this chapter. The findings and their associated interpretations are also explored in relation to existing literature.

These discussions are presented in two parts. The first part addresses the first half of the research question, "*What are the narratives of care provision by family carers?*" Here, the main issues arising from the analysis, such as the participants' role transformation, uncertainty, and autonomy in family caregiving towards the end of life, and the inability to perform a duty, are further explored within the context of previous research. Some of these issues are also briefly explored within Swanson's (1991) theory of caring introduced in Chapter 2.

The discussions progress by building the concept for moral distress plasticity, which addresses the second part of the research question, "*how do family carers describe*

*their experience of home-based care for people with a moderate to advanced dementia towards the end of life?"* Through a further exploration of internal conflicts in relation to earlier research, the discussions also ground a basis for the redefinition of moral distress.

## **6.2 Role transformation: a shift from pre-diagnosis relationship**

Transformation and transition are used synonymously to mean either "*a passage from one state, stage, subject or place to another*", or "*the act or process of changing completely*" (Merriam-Webster, n.d., transition section). The reference to these two words as '*an act*', at this point, may be taken to imply a purposeful pursuance of a change, which may be in response to either an intentional or unintentional experience or circumstance. This may portray transformation or the reported change as a choice upon which control may be exerted. While it is important to consider the extent of choice during this unexpected change given the unpredictable nature of dementia, such transformation may further acknowledge a process of liminality in the caregivers' experience given the element of ambiguity or uncertainty also identified in this study. An understanding of transformation is therefore also necessary in terms of a possible caregivers' liminality.

According to Sawyer et al. (2019, p.4), liminality is "*a state of in-betweenness and ambiguity that often occurs following a serious diagnosis.*" In similarity to transformation as described in this present study, liminality is also a gradual process, suggestive of caregivers' changes over time. A post-liminal state is also identified (Birt et al., 2017). This may also support the acknowledgement of a post-diagnosis role transformation in this present study. In contrast to liminality, transformation is considered a complete shift from a pre-diagnosis relationship with the recipient to a post-diagnosis alliance in this study. As an established sociological concept (Turner, 1974; Gennep 1960), liminality may also be described by how the

immediate environment is influenced by a person's new liminal identity (Birt et al., 2017). Liminality is also considered a rite of passage (Gennep, 1960), suggesting a view of an anticipated event following a diagnosis. Caregivers' transformation in this present study was unexpected. A reliance or consideration for sociological environments was therefore not necessary.

The transition theory by Schlossberg et al. (2006) offers an appropriate lens through which the findings of this study can be explored. Transition according to Schlossberg et al. (2006) is "*any event or non-event that results in changed relationships, routines, assumptions, and roles*" (Schlossberg et al., 2006, p.33). The wider scope of the theory focuses on adult developmental process for understanding experiences through life and exploring ways by which individual's adjustment and coping are influenced (Evans et al., 1998; Schlossberg et al., 1995). The issue of family carers' role transformation in this study suggests that an adjustment to the role is also required. While the experience of transition is established in critical care for its influence on nursing policies (Schmitt & Schiffman, 2019; Munck et al., 2018; St Clair, 2013), its existence is also applicable in dementia caregiving (Czekanski 2017; Singh et al. 2015).

Schlossberg et al. (2006) identified three categories of transition: anticipated, unanticipated and non-events. According to Schlossberg et al. (2006), unanticipated transition is characterised by its suddenness. This also describes the category of transition in this study, as an unanticipated response to a care recipient's dementia diagnosis. More emphasis has, historically, however been on transition in terms of care recipients' progress between stages of dementia (Cranwell et al., 2018; Papachristou et al., 2013; Neumann et al., 2001), and transfer to a care establishment due to increased care needs towards the end of life (Young et al., 2019; Afram et al., 2015). The knowledge of these transitions is crucial as it

informs the impact of transition on the person living with dementia. However, the nature of dementia suggests that some of these transitions are often predictable (Hirschman & Hodgson, 2018; Rose & Lopez, 2012), and may therefore not fall within the unanticipated category. These transitions may therefore be limited in increasing the understanding of the parallel experiences of family carers often recognised as the invisible second patients in dementia (Karg et al 2018; Brodaty & Donkin, 2009).

Transformation suggests a complete shift from a pre-diagnosis relationship with the recipient to a post-diagnosis alliance, whereby the family carer's role involves acting in the interest of the person cared for. This was possibly due to progressive loss experienced in line with the decline and characterised by care recipient's increased behavioural changes. Similar findings were reported by Blieszner and Shifflet (1990). In their view, transformation was regarded as a change in both pre- and post-diagnosis relationships, thus necessitating a redefinition of the caregiver to care recipient association from a 'normal relationship' where affection was possible, to a caregiver state where reciprocity of affection was difficult. Similar to the present study, Blieszner and Shifflet (1990) view this change in relationship as a loss. In contrast to the present study which involved single interview sessions, changes in post-diagnosis relationship were monitored by Blieszner and Shifflet (1990) over a six-month period. The findings of both studies, however, mutually identify progressive loss as a part of the changes to the relationship between the caregiver and the care recipient.

Understanding the motivation in role transformation is crucial to recognising its implications on caregivers' well-being. According to Schlossberg et al. (2006), the meaning of a transformation experience requires that the context, type, and impact are understood. In Swanson's (1991) view, role transformation may be considered

within the 'knowing' category of the theory of caring. Here, a caregiver actively pursues the knowledge of the care recipient's illness. Although this identifies that empathy and concern for the person cared for are felt by the caregiver, the findings in this study establishes that transformation may describe an unanticipated response to dementia. As suggested by Brown and Bond (2016), the reason for transitioning has a lesser impact on caregivers' well-being than the act of transitioning itself. Hence, a state of caregivers' unpreparedness for knowledge acquisition is also likely.

A sense of the inevitability of transformation is also conveyed in this study. It is suggested that motivation in role transformation may indicate a likely balance with a possible perception of inadequacy. In similarity to studies such as Greenwood and Smith (2019), and Singh et al. (2015), transformation may also have more in common with obligation than choice. This is similar to the finding by Al-Janabi et al. (2018), where choice was constrained by a duty to care. It is possible to consider, therefore, that transformation may be necessitated by the experience of uncertainty of what to do given the balance between choice, duty, and the unpredictability of post-diagnosis decline. This is also one of the findings of this present study. It may also suggest that the implication of transformation is far reaching as caregiving responsibilities increased progressively with the decline, while transformation remains stable.

This unpredictability in dementia further suggests that uncertainty is an attribute jointly shared by both the caregivers and care recipients (Polk, 2005). According to Mishel (2014; p.65), this uncertainty suggests an inability *"to determine the meaning of illness-related events, inclusive of the inability to assign definite value and/or to accurately predict outcomes"*. In this present study, uncertainty encompasses many aspects of caregiving in dementia. The issues of inclusion and continuity were highlighted as areas of concern to the participants, especially in consideration of what help was required and the decision-making towards the end of life in areas such as

the cost and appropriateness of care home placement. Some of the identified caregivers' uncertainty in this respect are represented in Fig 6.1 below.

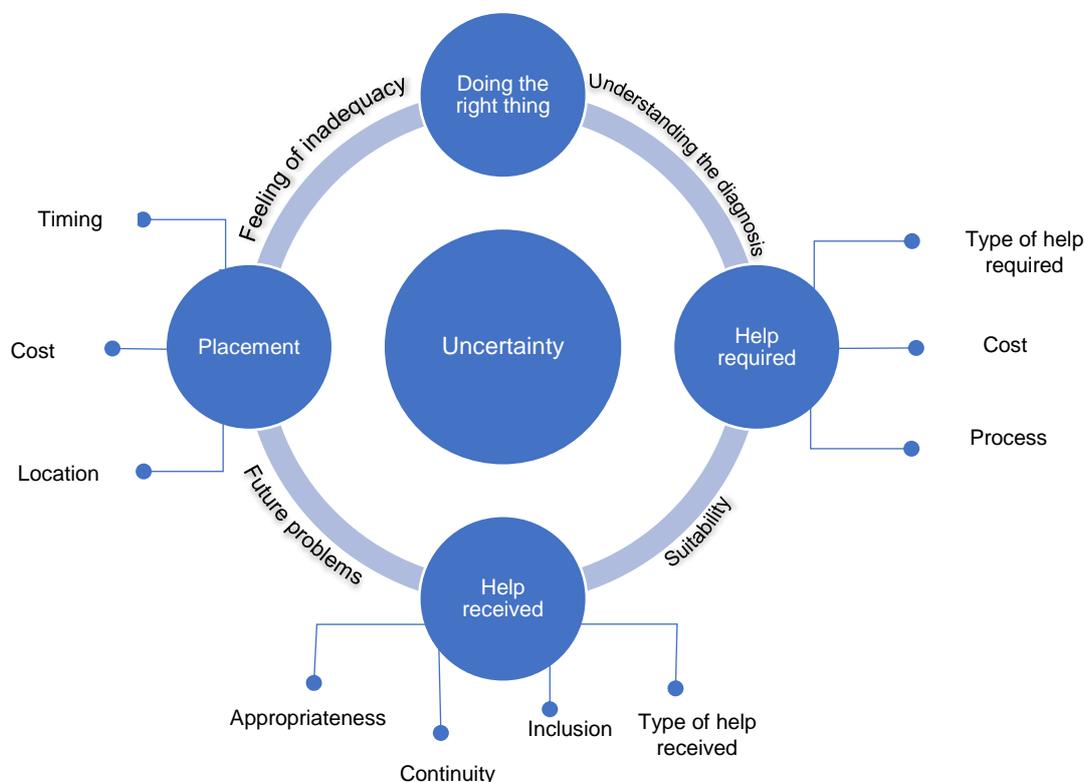


Fig 6.1: Uncertainty cycle in family caregiving for someone with dementia

Kupeli et al. (2019) also highlight the issue of uncertainty of the family carers. In similarity to this present study, uncertainty was felt by the family carers about end-of-life care decisions, such as whether palliative care was required for the person with dementia. Some of the reasons given for this uncertainty in their study included the lack of information and knowledge about the illness, confusion and sometimes the avoidance of discussions relating to end-of-life care. However, Kupeli et al. (2019) did not identify uncertainty in relation to the fear of the unknown. The findings in this present study suggest that the progressive nature of the dementia causes a constant fear described as the *'anticipation of what may happen next'*. The uncertainty in the extent of decline may therefore be one of the reasons for caregivers' desire for making a meaning of their role transformation and the natural expectation to act. It

may also suggest a reason for the difficulty in ascertaining the appropriate timing for acting or 'doing something' as also suggested in the present study.

The identification of powerlessness and uncertainty within role transformation is supported by Wang et al. (2019). The study highlights that uncertainty is indicative of the high emotional tie between the caregiver and the care recipient. The feeling of powerlessness within this experience was, however, described as feeling a sense of lack of control over the illness progression and its implications for the caregiver-care recipient relationship (O'Shaughnessy et al., 2010), as well as an entanglement in this new phase of life (van Wijngaarden et al., 2018). The resultant impact on the caregiver is viewed, also, as a dichotomy between acceptance and realism of the prospective future related not only to the illness progression and how to manage it, but also with its possible duration (Hellström et al., 2017; O'Shaughnessy et al., 2010). Consequently, this also has an implication for the duration of their role transformation given the unpredictability of illness progression.

Similar to the findings by O'Shaughnessy et al. (2010), caregivers also expressed a feeling of powerlessness to influence a change in decline. Towards the end of life, progressive decline meant that care recipients' disinterest was prevalent. Progressive decline was therefore regarded by the caregivers as a gradual erosion or loss of the recipient's identity. Indeed, Twig and Buse (2013) identify that erosion of personhood and loss of identity are possible through dementia. According to Austin et al. (2016), this is a challenge to relationships between the caregiver and the person cared for. It is also a challenge to caregivers' adjustment in their new role. In keeping with the present study, where participants described the person cared for as 'gone while still alive', Austin et al. (2016, p.17) further highlight a resultant desire of the caregivers to *"try to hold on to what the person with dementia used to be"*. It is therefore likely that the powerlessness felt in altering the course of dementia, may be an

acknowledgement of a finality, especially in relation to diminished cognition towards the end of life.

The expected duration of a transformation, according to Schlossberg (1981), is representative of adaptability. The uncertainty of the duration of an illness, however, causes the greatest degree of stress. Thus, a permanent change from an illness, such as described by the experience of dementia in this present study, and as also suggested by Schlossberg (1981), may be viewed differently from a change that develops over time. Given that a change caused by dementia also develops over time, there is a possibility that a prolonged duration of caregiving may suggest a difficulty in transformation as described in this study. This reasoning is also supported by van der Flier and Scheltens (2005), which suggests that although life expectancy varies considerably, people with dementia usually survive on average, between 7 and 10 years following the onset of symptoms. As such, a conclusion may also be reached that the permanence of transformation offers no positive solace as Schlossberg (1981) suggested.

According to Schlossberg et al. (2006), the existence of a transformation is only definable by the person experiencing it. Findings from this present study however show a common difficulty in participants' ability to describe the exact point of their role transformation. Thus, defining their experience as a transformation needs further clarification. A question therefore remains on the specificity of timing of a transformation occurrence, as this may aid the caregiver's preparation once a diagnosis is received. It is possible to consider that there is a caregiver's '*awakening to*' a new role, distinctly different from a role previously occupied. This may also depict role transformation as an occurrence in line with a gradual, but unpredictable decline.

It is possible that a new relationship is formed as a result of a role transformation. It is also possible to consider that the difference in the quality of the relationship between

the caregiver and the care recipient pre- and post-caregiving has an impact on the caregiver's wellbeing (Quinn et al., 2009), such as the feeling of loss, as suggested by Kepic et al. (2019). This has also been identified as a common stressor in caring for someone with dementia (Zarit & Edwards, 2008). Although transformation remained stable through the illness trajectory, caregiving responsibilities increased progressively with the decline. The motivation for sustenance of the new relationship however required the existence of a pre-diagnosis alliance or relationship between the caregiver and the care recipient. Thus, a need for the preservation of the care recipient's personhood or a participant-perceived value of the care recipient may be an important determinant of role transformation timeline. In recognition of a new illness-based relationship therefore, it may also be possible to view role transformation as an extension of a pre-diagnosis relationship.

### **6.3 Loss: an issue for autonomy and erosion of independence**

The review of the literature review in Chapter 2 establishes a description of loss as the recognition of the absence of care recipient's valued personality (Lindauer et al., 2016; Adams & Sanders, 2004). This description also encompasses an experience of a paradoxical feeling which was described as holding on to what remains of the care recipient (Lindauer et al., 2016), or holding on to someone who was already gone (Lindauer et al., 2016; Adams & Sanders, 2004). A combined description of loss in this study may be established as a gradual erosion of the recipient's identity or a valued participant-perceived attribute as the disease progressed. However, this process is likely to be incomplete until cognition is totally diminished which may acknowledge a finality in existence, as well as a marked powerlessness to alter the course of illness progression.

A key differentiation was also made in the literature review in Chapter 2 between *personified loss*, as a description of caregivers' perception of own loss in terms of

social roles and fulfilling own needs, and *personified value*, which describes loss in recognition of a caregiver-attributed value in relation to care recipient's changes as the illness progresses. The findings in Chapter 5 of this current study suggest that these views are also shared by the participants. Participants' internal conflicts however appear related only to loss in terms of *personified value*. As a direct anticipation of care recipient's increased reliance on family carers due to cognitive decline, an acknowledgement of the loss of their defining characteristics suggests that a loss of autonomy is also possible. Given that progressive decline also suggests a further increase in reliance, the impact of possible care recipients' disempowerment is therefore questioned. Findings from this present study suggest that indeed, the family carers' powerlessness over the decline may be a source of concern in relation to loss of autonomy. While powerlessness was acknowledged by the participants' narratives, increased reliance was however an expected outcome.

Diminished cognition is one of the hallmarks of a progressive decline in dementia (Anuja et al., 2018; Schmidt et al., 2011; Geschwind et al., 2007). Behavioural changes over time, as established in this present study, are also reported elsewhere (Hodge et al., 2020; Müller-Spahn, 2003; Hooker et al., 2002). The rapidity of decline, however, is mostly characteristic of the severity of the illness and the type of dementia diagnosed (Tarawneh & Holtzman, 2012; McLaughlin et al., 2010). As the severity of decline increases, the level of care recipient's reliance also increases considerably. According to McLaughlin et al. (2010, p.4), reliance or dependence, refers to "*the measurable impact of changes in cognition, function, and behaviour that result in an increased need for assistance.*" Increasing reliance is therefore considered an important predictor of caregiver's stress throughout the course of dementia (McLaughlin et al., 2010). The impact of care recipient's changes over time, according to McLaughlin et al. (2010), show that cognitive decline necessitates an increased reliance on others for memory-related activities. Through the care

recipient's increasing inability to perform physical tasks such as getting dressed independently, a functional decline is therefore also experienced which necessitates an increased reliance on others and leads to a loss of functional autonomy (McLaughlin et al., 2010).

The findings in the present study also support these claims. The progressiveness of decline suggests a gradual erosion of the care recipient's independence, the loss of autonomy through increased reliance on the others (including the caregivers themselves), is a source of fear for the caregiver. As an illustration, the narrative by E1 in the study describes a caregiver's fear of a care recipient being disregarded as a person through their loss of autonomy. In E1's case, this fear was related to his father's inability to have a voice in care considerations. His comment: "*...not just a diagnosis. He's still a person*" portrays that there is a possibility for his father as a care recipient to be viewed as a diagnosis rather than being treated as a person. As a mechanism for ensuring that autonomy continues for longer, however, a choice of staying positive and including his father in the process was made by staying truthful with him about his decline.

The fear of care recipient's loss of autonomy was further explored by Smebye et al. (2016) as a caregiver's wish for addressing an ethical dilemma in respect of upholding the principle of non-maleficence. In this instance, the dilemma was considered as a balance between the value of the autonomy and the need to prevent harm or distress (Smebye et al., 2016). The findings in this present study have shown, however, that participants' perception of caregiving sustenance post-diagnosis was based on the existence of a pre-diagnosis relationship. This also has implications for their role transformation. Thus, rather than view their experience as a dilemma, which suggests that the principle of non-maleficence is limited only to a choice between the value of care recipient's autonomy and the need for harm prevention, consideration for caregiver's distress in fulfilment of their caregiving duty

post-diagnosis is also warranted given the difficulty in knowing what to do as previously discussed.

#### **6.4 Duty: an issue for caregiver's moral choice and a sense of agency**

Park et al. (2018) suggest that an increased loss of functional autonomy is a usual predictor of institutionalisation. While this assertion may be true, participants in this present study expressed a preference for keeping their care recipients at home for as long as possible in fulfilment of a duty and keeping pre-dementia promises, such as marital vows. This sense of duty is considered one of the motivators for family caregiving (Tretteteig et al., 2017; Brodaty & Donkin, 2009). According to Martin-Cook et al. (2000), it also affords the caregiver the possibility of deriving a positive sense of performing an important job. As such, it may also help them with role adjustment considering the emotional requirements of caregiving (Martin-Cook et al., 2000). It is however also a cause of psychological distress as identified by Brodaty & Donkin (2009), and in some cases, it may also present as a reason for resenting the caregiving role (Brodaty & Donkin, 2009).

It has been shown in this present study that powerlessness in fulfilling a duty may be another probable reason for distress and resentment of the caregiving role. According to Tretteteig et al. (2017), being supportive is an expression of own expectation. While this may suggest that fulfilling a post-diagnosis caregiving duty is a caregiver's choice, powerlessness in fulfilling this sense of duty may also suggest a personal inadequacy. This understanding is also established in the present study, especially as illustrated by the narratives of participants who identified as couples. In their view, the ability to fulfil a post-diagnosis caregiving sense of duty is a natural way of keeping pre-dementia diagnosis promises. The sense of duty may however be viewed as a means of 'doing for' the person cared for (Swanson, 1991). According to Swanson (1991), 'doing for' may be considered an enablement by which caregivers

fulfil the care recipient's pre-dementia abilities. Mirroring the present study, however, this may also be an acknowledgement of a loss, or acceptance of a state of illness over which the caregiver feels powerless.

The sense of duty affords the caregiver a sense of agency (Smebye & Kirkevold, 2013). In this present study, the participants provided care to people within moderate to advanced stages of dementia. As such, progressive decline was already established. In such situations, the caregiver's sense of agency involves taking responsibility for the conduct of the caregiving process (Moore, 2016). Caution is however required to differentiate between this attribution of a sense of duty and participants' sense of agency, given that reference to a 'sense of agency' as 'taking responsibility' for caregiving may connote a notion of caregiving as an obligation without choice. The participants did not attribute the meaning of their sense of duty to an obligation. Instead, an acknowledgment of their sense of agency was made in consideration of a moral choice for continued home-based caregiving. The caregiver's sense of agency is considered a necessity given the progressive decline in both cognitive and functional abilities of the care recipient. Thus, the fulfilment of the caregiver's sense of agency may also be perceived a fulfilment of their moral agency.

The ability of the caregiver to fulfil their moral agency may establish non-fulfilment as powerlessness and a personal inadequacy. As previously discussed, fulfilment of a post-diagnosis caregiving duty represents a personal choice, a view which was poignantly expressed by the narratives of help seeking presented in Chapter 5. Guilt was initially attributed to a failure in receiving adequate help and expressed in relation to the care home placement of the person cared for. Following the placement of the person cared for in a care home, the perception of guilt was further expressed as an admission of the caregiver's inadequacy in doing the best for the care recipient. Similar accounts of guilt and a feeling of inadequacy was also expressed in

anticipation of a prospective move into a care home facility. These accounts were also attributed to a difficulty in getting help deemed appropriate to the level of decline. Hence, it is possible to consider powerlessness or an inability to fulfil a moral agency pre-and-post care home placement as a probable cause of a caregiver's feeling of inadequacy and guilt.

## **6.5 Moral distress plasticity in home-based caregiving**

A growing school of thought considers individuals to be subjects of their experiences (La Fontaine et al., 2016; Baker, 2015). With first-person perceptions, such as those reflected in this present study, such experiences are social entities shaped within interactions rather than within an existential vacuum (Baker, 2015). Within a shared social construct such as the home setting, the description of two similar feelings, such as internal conflict and moral distress may be equivocally interpreted as being descriptive of each other or somewhat interwoven, given the similarities of their experiences, and/or if the characteristics of their perceptions are indistinguishable from their actual experiences.

Some of the experiences identified in this study, such as guilt, anxiety, frustration, anger, powerlessness, and uncertainty in home-based caregiving, in some instances are referenced as internal conflicts (Morris et al., 2018; Lamahewa et al., 2018; Swallow, 2017; Smebye et al., 2016; Bunn et al., 2012), while also regarded as moral distress in others (Milne, 2018; Fumis et al., 2017; Smebye et al., 2016; Pijl-Zieber et al. 2016; Borhani et al., 2014). Evidence from this study suggests that participants' internal conflicts and the moral distress experienced are two distinct yet interrelated feelings. Thus, the two concepts may also be individually addressed through a better understanding of the plasticity of their interrelationship.

Plasticity is not a new concept in understanding of human behaviours. Although mainly discussed in the field of neuroscience in terms of the developmental process

of the brain in coping with changes over time (Kim, 2020; Pauwels et al., 2018; Park & Bischof, 2013), it is also recognised in social interactions in relation to the importance of the psychological factors that determine the feelings of distress and the need to help others, such as friends and relatives (Cantor et al., 2019; Klimecki, 2015; Daniels, 1979). This is also considered a crucial basis for establishing the individual autonomy and capacity to empathise or differ in feelings with others within a shared social situation (Singer & Klimecki, 2014). Given that these are also some of the attributes that describe caregiving within a domestic home setting, consideration for plasticity of family carers' experiences may also be appropriate.

The occurrence of dementia within a social situation or construct such as a family, can be a source of emotional devastation (Meuser & Marwit, 2001). Similar to Schulz and Eden (2016) and Day and Anderson (2011), the findings in this present study show that within the moderate to advanced stages of dementia, caregivers acknowledge their own feelings of loss while also identifying with the care recipient's experience. According to Eisenberg (2000), this capacity to share or identify with the care recipient's feelings or sufferings may also describe an emotional state of concern also considered a precursor to a caregiver's helping behaviour. In Figley's (2002) view, concern, and an ability to empathise are motivating factors necessary for responding to the care recipient's experiences. Where the duration of caregiving is prolonged, however, compassion stress is also likely (Figley, 2002). As such, the long duration of caregiving in dementia may therefore be a cause of family carers' stress.

The feeling of inadequacy in offering help by a caregiver is often a perception of an unfulfilled duty as shown through the findings of this present study. This perception is also an important key to understanding the association between internal conflict and affect (Sato, 2005). Although Sato (2005) did not expand further on the meaning of affect in this context, it is assumed based on other studies on affective emotions,

such as Fernandez et al. (2019), and Zadra and Clore (2011), that this association portrays the recognition of a desire to act. A desire to act in this context is incongruent with the ability to act as highlighted by Figley (2002). The ability to empathise, 'show concern', or 'have a desire' to act is a motivating factor for responding to care recipient's suffering. Hence, it is considerable that affect may also be a responsive emotion which evidences a possible experience of an internal conflict for taking action.

Internal conflicts are expressed through emotions, and a caregiver's empathy with the care recipient may be a responsible factor (Roberto et al., 2019; Monin & Schulz, 2009). Along with this empathy, previously identified as a precursor to a caregiver's helping behaviour, expressions such as anger, guilt, frustration, and anxiety are indeed characteristic examples of emotions associated with their concern. Whereas being concerned motivates a desire to act (Tretteteig et al., 2017; Kim et al., 2016), it may not, however, compel a caregiver's moral action or inaction. Instead, being motivated justifies an action or a choice to act (Kraut, 2020; Alvarez 2017). In the context of this study, this possibility of a moral action or inaction being dependent on the caregiver's choice makes it plausible to also consider the expressions of their feelings as being subjective in nature, which may also reflect the association of their affective emotions with their internal conflict (Scarantino & Sousa, 2018; Monin et al. 2009; Sato, 2005).

As previously stated, a motivation to act due to being concerned is distinctively different from taking a moral action or inaction. Through the findings of this study, it has been suggested that a choice to act is pertinent to the perception of caregiver's fulfilment of a moral duty. Indeed, this was also a basis for presenting their moral choice for continued home-based caregiving. Although there was no evidence to suggest that caregiving was perceived as an obligation, the internal conflict

expressed may be reflective of an inconsistency between perception and actual experience (Sato, 2005). As such, congruence between a perceived expectation and actual experience may either reduce internal conflict or cause it to be non-existent due to the reduced anxiety, which is also a symptom of internal conflict (Sato, 2005).

In 1954, Alfred Adler also highlighted a foundation for internal conflicts as a feeling of 'being inferior to' - or holding a perceived 'inadequacy' (Adler, 1954). Like Sato (2005), Adler (1954) described this feeling as an emotion, and as a common cause of anxiety, which was a mismatch between self-perception and experiences. In this present study, a feeling of inadequacy, such as decision-making regarding care needs, was also expressed by the participants. In their experience, this showed a misalignment between perception of duty, and the challenges faced in its fulfilment through the progressiveness of decline, such as difficulty in help seeking or the unsuitability of help received which sometimes necessitates a care recipient's placement elsewhere.

The process for seeking help was shown to cause anxiety and uncertainty in knowing what to do. According to the participants, the unsuitability of help received in comparison to the level of decline in some instances was also a source of guilt. These experiences are characteristics of their internal conflict as has been discussed in this section. However, the feeling of inadequacy reflects a perception of their loss of autonomy where performing a moral duty is required. Where the performance of a moral duty is difficult or impossible, as previously shown in the findings, the feeling of being a failure also gives evidence of their powerlessness.

From these perspectives, it is plausible to conclude that the feeling of distress to a caregiver's morals, or moral distress, may be considered a challenge experienced at the instance of the necessity of a moral course of action in fulfilment of a duty, rather than an emotional feeling, characteristic of being conflicted internally. The element of

the 'unknown' in selecting the right course of action such as described by the participants in this study, may therefore also be viewed differently from a feeling of being conflicted, for which an action is not required. This may also form a foundation for viewing emotions such as guilt, anxiety, frustration, anger, or powerlessness, as being characteristic feelings of the caregiver's internal conflicts. As such, internal conflict itself may be viewed as the characteristic moulding hallmark of a caregiver's moral distress.

In Chapter 1 of this study, moral distress, as originally defined is "*when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action*" (Jameton, 1984, p.6). It has also been recently redefined as "*the internal conflict that occurs when you know the ethically appropriate action to take but are unable to act on it*" (Browning & Eckel, 2018, p.4). The discussions in this section have set a foundation for the concept for moral distress plasticity, which addresses the second half of the research question, "*how do family carers describe their experience of home-based care for people with a moderate to advanced dementia towards the end of life?*"

It has been shown that participants' experience of internal conflicts is described through the expression of their affective emotions such as anger, anxiety, and frustration. Their moral distress was, however, experienced at the instance of the necessity of a moral course of action in fulfilment of a moral duty. It is possible to conclude, therefore, that moral distress may not be limited in its regard as a phenomenon that occurs only as a result of not knowing the right thing to do or as a result of the inability to act due to a constraint, but as a result of the necessity of an action. As such, moral distress plasticity may be viewed as the ability of the emotions associated with internal conflicts to mould the caregiver's moral distress at the instance of the fulfilment of a duty.

## **6.6 Moral distress triangle framework revisited**

In the development of the moral distress triangle framework in section 1.4.1 of this study, three key assumptions were set out. In these assumptions, the understanding of moral distress was identified as an interplay between the *capacity, knowledge and the code* or rules. The findings have demonstrated that these three assumptions also exist within an informal setting such as a domestic home. The findings suggest that following a diagnosis of dementia, a transformation occurs within the capacity or role in which the family carer functions, as a complete shift from a pre-diagnosis relationship with the recipient to a post-diagnosis alliance. A difficulty however exists in describing the exact point of transformation. Thus, an experience of moral distress is described in relation to the care recipient's autonomy and the participants' own view of caregiving duty as an issue for moral choice and a sense of agency.

The findings in this present study also suggest that contrary to moral distress common description within an assumption of knowledge vis-à-vis knowing what to do (Browning & Eckel, 2018; Jameton, 1984), an uncertainty of the right course of action following a dementia diagnosis was a factor which influenced role transformation. For the participants in this study, the motivation for the sustenance of caregiving post-diagnosis was however based on the existence of a pre-diagnosis relationship with the person cared for. Furthermore, the natural expectation of the caregiver to act through the performance of their caregiving duty demonstrated a desire to make meaning of their role transformation which also support this study's conclusion of moral distress as a feeling experienced due to the necessity of an action.

## **6.7 Conclusion**

The research question was addressed in this Chapter in two parts. In the first part, some of the main issues arising from the analysis in Chapter 5 were addressed, such as the participants' role transformation and their perception of the fulfilment of a moral

duty. It was established that role transformation was an unanticipated response to a care recipient's dementia diagnosis. As a complete shift from a pre-diagnosis relationship with the recipient to a post-diagnosis alliance, it was considered an extension of a pre-diagnosis relationship, and in recognition of a new illness-based relationship. Although a common difficulty exists in describing the exact point of transformation, the family carers' narratives of care provision describe an experience of moral distress in relation to the care recipient's autonomy and the participants' own view of caregiving duty as an issue for moral choice and a sense of agency.

The second part of the research question was addressed through the development of the concept of moral distress plasticity. It was established that feelings such as anger, guilt, frustration, and anxiety that the family carers used to describe their experience of home-based care for people with a moderate to advanced dementia towards the end of life, were characteristic of affective emotions associated with internal conflicts. Moral distress was, however, experienced at the instance of the necessity of a moral course of action in fulfilment of a moral duty. As such, their moral distress may be viewed as being moulded by their internal conflicts.

## **Chapter 7: Conclusions and recommendations**

### **7.1 Introduction**

The purpose of this study was to explore how family carers describe their experience of home-based caregiving for someone with a moderate to advanced dementia towards the end of life. The research question asked was *“What are the narratives of care provision by family carers, and how do they describe their experience of home-based care for people with a moderate to advanced dementia towards the end of life?”* Three objectives were set to identify whether internal conflicts were experienced by family carers and if this signifies that moral distress were also experienced.

Within this study, the experience of internal conflicts and moral distress by the family carers for people with a moderate to advanced dementia within the domestic home setting has been explored for the first time. Ways in which these are expressed are also shown. In this study, it has been shown that the moral distress experienced by family carers may differ from that experienced by health and social care professionals where more emphasis is placed on institutional constraints. In this final chapter, the contribution of this study to current knowledge and implications for policy and practice are presented. Suggestions of possible avenues for future research are also made. The reflections on the strengths and limitations of the study were based on the narrow focus of the study in terms of the stages of dementia considered, the setting and the group of carers. Finally, the overarching conclusion of the thesis is presented, which may inform how the needs of home-based family carers for people with a moderate to advanced dementia may be better met.

### **7.2 Contribution of the study to knowledge**

Poor quality of life and negative experiences are usually reported by people who look after individuals with dementia. Some of these experiences as described by caregivers unrelated to individuals living with dementia, such as nurses and other

healthcare professionals, have been explored and described as moral distress. However, the account and experiences of family carers or people who look after individuals with dementia in an unpaid capacity within a domestic home setting were yet to be investigated. In this present study, the experience of the people who provide home-based care to individuals with dementia within the moderate to advanced stages towards the end of life has been explored.

The understanding of moral distress has been advanced as a challenge experienced at the instance of the necessity of a moral course of action in fulfilment of a moral duty. While the internal conflict experienced was described as the characteristic moulding hallmark of moral distress, the association between moral distress and internal conflict was described in terms of a plasticity. Thus, the gap in current knowledge regarding the experiences of family carers for people with a moderate to advanced dementia within a domestic home setting towards the end of life has been narrowed.

### **7.3 Implications for policy and practice**

The evidence presented in this study show that a limited attention may have been focused on post-diagnosis support in the UK. Currently, there is no clear national or local policy on managing stage-specific support for family carers, post-dementia diagnosis. Examples of these policy differences are reflected in practices between Scotland and England, whereby in Scotland, every person newly diagnosed with dementia is entitled to at least a year of post diagnostic support. This is however not the case in England. Previous studies such as O'Shaughnessy (2015) and Cheston et al. (2014) have highlighted this issue of post-diagnosis support and recommended an improvement due to its being fragmented and usually provided by multiple organisations. Cheston et al. (2014) have also warned that due to an absence of a

national standard for mapping available support, the problem with post-diagnosis is a prevalent concern.

The findings of this study indicate that a policy on stage-specific post-diagnosis support for family carers within the moderate to advanced stages of dementia may be necessary. The implementation plan of the Prime Minister's Challenge on Dementia 2020 indicates that there is a government ambition to enable people with dementia to live and be cared for in their own homes for longer in the UK (Department of Health, 2016). Apart from the use of assistive technology, which was suggested as one of the ways to partially achieve this ambition, the role of the family members who provide care was also highlighted (Department of Health, 2016).

In support of this ambition and in similarity to the evidence by Lord et al. (2016), participants in this present study also expressed a desire to continue home-based caregiving and regard this as the fulfilment of a moral duty. Etkind et al. (2017) has however warned that the number of people providing home-based care for individuals with dementia in the UK is likely to quadruple by 2040. Based on the findings of this thesis, coordinated effort is needed to ensure that such people receive more support. An implication for the absence of such support suggests that Prime Minister's challenge may not be achieved for caregivers of people within the moderate to advanced stages of dementia. As suggested in this present study, the reduction of the unsuitability of support received, especially within the moderate to the advanced stages of dementia, is crucial.

Fulfilment of a moral duty is important to caregivers, but their experience of isolation and feelings of abandonment have also been highlighted in this present study. A change in practice is therefore required to enhance carers' experience, especially for people new to the role, as the number of people caring informally in the UK increases. As highlighted in this present study, knowledge about a stage-specific support system in caring for people with dementia is limited. Such a support system

is recommended for minimising the feeling of isolation and abandonment, especially given the likelihood of benefitting people who provide care within the domestic home setting. Within this support system, the caregivers' experience of changes in the person cared for may be sought at frequent intervals to ensure that provision of care and support is targeted in line with the disease trajectory at both the caregiver and the person cared for. As increased decline is reported by the caregivers, it is possible that more support is required for both the caregiver and the person cared for. It is believed that such support system would encourage an active provision rather than a reactive engagement in response to crisis in post-diagnosis caregiving for someone with dementia within the home setting.

#### **7.4 Future research**

There are several questions raised by this study about the experiences of the family carers within a domestic home setting. The findings of this study have laid a foundation for understanding the experience of moral distress and internal conflicts within this group. While the association between their moral distress and internal conflict was described in terms of a plasticity, the possibility of all internal conflicts in moulding caregivers' moral distress remains unexplored. It also remains unclear whether all forms of internal conflict could lead to an experience of moral distress. A future research question to explore these areas may be: *“are all forms of internal conflict capable of moulding the caregiver’s experience of moral distress?”*

A further development of moral distress plasticity may also be necessary, given the relationship established between internal conflict and the caregiver's moral distress in this present study. This is crucial to explore whether a plasticity quotient exists such that the more expansive the internal conflict becomes, the more acute the moral distress experience. The possibility of an increasing moral distress experience was beyond the scope of this present study. It is probable, however, that due to the

suggestion of internal conflict being a hallmark of moral distress in this present study, the existence of the moulding association between these two experiences may also suggest that the increase in one, leads to the increment of the other. A process for reporting dementia-related changes as they occur may be introduced as an intervention for alleviating the impact of either of these two experiences at an early stage of the transformed role. Hence, a potential research question may therefore be suggested as: *“does an increase in internal conflict lead to an increased moral distress experience?”*

## **7.5 Strengths and limitations**

The strength of this study relies on the considerable effort made to ensure that the scope and objectives of the research were clear from the beginning. This was achieved by having a research question and a set of research objectives. The adoption of a textual narrative synthesis of studies ensured the successful review of the commonality and differences of caregiving experiences at both the moderate and advanced stages of dementia was possible. The in-depth collection of data and detailed exploration of participants' accounts also ensured that narratives were precisely developed using their verbatim words. This helped present the participants' novel representation of personal stories of home-based caregiving within the moderate to advanced stages of dementia.

A high level of interest was expressed at the initial stage of recruitment in this study. The recruitment rate was however low through the two routes (carer support groups and domiciliary care agencies), considered as the primary routes for potential participants' introduction. Within these two routes, a common factor of reluctance in acting as a site study coordinator was encountered. While some participants were successfully recruited via the carer support groups, recruiting through the domiciliary care agencies was more difficult. An initial interest was indicated by the domiciliary

care agencies approached. However, potential participants introduced from these agencies did not make contact, and this necessitated the submission of two ethics amendments for further routes to be added. While this did not lead to a substantial limitation in the quality of collected data, it may be that additional recruitment of participants through the domiciliary agencies would have added more diversity in age group or race categorisation of experiences explored in the study.

It is necessary to re-iterate that enrolment into the study was voluntary. However, the participants were white and mostly educated individuals. While this may suggest that a diverse account of experiences was not considered, the issue of race and educational background was not salient to the purpose of the study. Indeed, it is unclear whether collection of a more diverse account of experiences would have been achievable if people of other ethnicities and educational backgrounds had been recruited. This may form the focus of a future research. The exploration of accounts within the moderate to the advanced stages of dementia was also considered a limitation given that accounts from other stages were unexplored in the study. The scope of the study suggests that the findings reported serve a purpose of answering the research question.

## **7.6 Conclusion**

The research question of this study has been answered. It has been established that the family carers who participated experienced both internal conflict and moral distress. Whilst internal conflict was described through participants' expression of their affective emotions such as anger, anxiety and frustration, moral distress was experienced at the instance of the necessity of a moral course of action in fulfilment of a moral duty. The contribution of this study to current knowledge has been presented in this concluding Chapter, as well as the implications for policy, practice, and research.

It must be stated that this study only considered those feelings reported by the participants interviewed. It is therefore inconclusive to suggest that all feelings associated with internal conflicts are capable of moulding a caregiver's moral distress, especially in home-based caregiving for people with a moderate to advanced dementia towards the end of life. It is pertinent to highlight, however, that within a shared social construct such as the home setting, the description of two similar feelings, such as internal conflict and moral distress may be equivocally interpreted as being descriptive of each other, or somewhat interwoven given the similarities of their experiences and/or if the characteristics of their perceptions are indistinguishable from their actual experiences. It is possible that this confusion is due to both internal conflict and moral distress being feelings which caregivers experience during home-based caregiving or the capability of these two experiences being felt simultaneously, as a result of their moulding interrelationship.

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## Appendices

### Appendix 1: Electronic search strategy conducted in MEDLINE

Period: from January 1984

#### Searches

1. MH "dementia+"
2. TX dement\*
3. TX alzheimer\*
4. TX "lew\* bod\*\*"
5. TX FTLD OR FTD OR frontotemporal OR vascular dement\* OR mixed dement\*
6. 1 OR 2 OR 3 OR 4 OR 5
7. TX carer\*
8. TX caregiv\*
9. TX care-giver
10. TX spouse-caregiver\*
11. 7 OR 8 OR 9 OR 10
12. MH "qualitative research+"
13. MH qualitative research or qualitative study or qualitative methods or interview
14. MH "focus groups"
15. TX exploratory research
16. TX ethnography qualitative research
17. TX content analysis in qualitative research
18. MH "grounded theory"
19. 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18
20. 6 AND 11 AND 19

(MH = MESH Heading; TX =All Text Fields)

**Appendix 2: Review of experiences of caring at moderate to advanced stages of dementia**

Experience	Quotes/Comments	Paper
Increased caregiving responsibilities	<p><i>“My free time, my hobbies, solitude” (Caregiver at moderate stage)</i></p>	Adams and Sanders, 2004 p202
	<p><i>“My health, trying to keep well and getting sleep” (Caregiver at moderate stage)</i></p>	Adams and Sanders, 2004 p202.
	<p><i>“I don’t have life. I don’t have privacy. Sometimes I need to lie to her (mother-in-law) that I’ll be leaving for outstation, so that I would have time for me and my family” (P4- caregiver at moderate stage)</i></p>	Idura et al., 2018 p98
	<p><i>“Very challenging. I have to take care of her (patient) and my children are 7, 5 and 2 years old, and one [more] is coming (pregnant). The feeling is just like I have 4 children since she is just like a child now.” (P3- caregiver at advanced stage)</i></p>	Idura et al., 2018 p96
	<p><i>“I don’t have life. I don’t have privacy. Sometimes I need to lie to her (mother-in-law) that I’ll be leaving for outstation, so that I would have time for me and my family.” (P4-caregiver at moderate stage)</i></p>	Idura et al., 2018 p98
Burden	<p><i>“it just wears on you.”</i></p>	Lindauer et al., 2016

Positive aspects of caregiving		
Passivity (at moderate stage)	<i>"My husband often scolded me fiercely with foul language. One morning, he suddenly sprinkled water at me for no reason!"</i>	Chan et al., 2010 p166
Passivity (at advanced stage)		
Reliance and advantage of external support availability (day-centre use at the moderate stage)	<i>"We go for regular talks by the Alzheimer Centre. And then we got more realization about her—what to expect. I think we are better equipped now lah." (P1)</i>	Idura et al., 2018 p97
Limited availability of external support (family and day-centre use at both stages)	<i>"At one point, I need to send him (father) to a day care centre since I need to work and no one can take care of him after my mother passed away. However, there were limited places in the day care that suits him and all of them are expensive. I ended up taking loan from a bank." (P8)</i>	Idura et al., 2018 p97
	<i>"It was extremely difficult at the very beginning. I always felt lonely, as no one in my family was willing to give me a hand. My husband scolded my mother ...oh no, not only my husband ...but also everybody at home. All of them hated her."</i>	Chan et al., 2010 p166
	<i>"I wish I had more support from my two daughters." (VB)</i>	Smith et al., 2001 p18
	<i>"Much of the time I carried the load myself." (LN)</i>	Smith et al., 2001 p18

	<i>"I thought my brother would take my mom. I thought he would put in an appearance. Once he took her for three days. I had to call him to take her. I was angry at my brother because he didn't care for mother. He should have stood up and said, I'll help my sister." (JL)</i>	Smith et al., 2001 p18
Caregivers' obligation to provide care	<i>"When I first took on my mother I had a..... huh.... image of her as a mother. Because think about it, I don't think she's going to be around forever. It's like filial piety." (P1)</i>	Idura et al., 2018 p98
	<i>"This is the only lifetime experience. You don't have another chance if they're gone. This is the moment to cherish. If you have that attitude, you should be able to cope with it in a more positive manner." (P11)</i>	Idura et al., 2018 p98
Care as a sense of duty	<i>Although I am not fond of my father, I feel it is my duty to help him in his current difficult situation. He left our family when I was a teenager; since then, contact has been sporadic. In spite of this, I have no reason to avenge myself on him for what happened to us.</i>	Tretteteig et al., 2017 p449
Caregivers' religious expectations	<i>"I would encourage churches to be more supportive. I don't feel that the church gave me the support I needed. When I took him (her husband) to an adult day center and he hated it. So, I went to my pastor and said, I have to have help. The pastor sided with him and decided that he didn't need to go to the adult day center. I said, look I need help. I can't take this. The pastor's response was, you said your marriage vows, for better or for worse, until death do you part. You have had the better, this is the worst and it is your responsibility to take care of him." (AW)</i>	Smith et al., 2001 p21

Personified loss	<i>"...I've had to quit my job to take care of her and I do not attend church anymore."</i>	Adams and Sanders, 2004 p202
	<i>Everything is lost to you... because you're concentrating on that person and the only time you have some time off is when you just actually steal it, you have to take it."</i>	Lindauer et al., 2016 p737
Personified value	<i>"I miss the sparkle in my mother's eye. I can't get adjusted to that empty stare or the knowledge that most of the time she doesn't even know what I am saying." (Caregiver at advanced stage)</i>	Adams and Sanders, 2004 p202
	<i>"Just having talks with my mom. To ask her advice on anything. I miss her love for me and all the love she gave my children." (Caregiver at advanced stage)</i>	Adams and Sanders, 2004 p202
	<i>"It's a blessing to have her still here." (Caregiver)</i>	Lindauer et al., 2016 p738
	<i>"I look at him sometimes and think the "he" I know is no longer there. Once in a while, there is a flash of the person he once was and then it is gone. This makes me sad. I would rather have him all here or all gone."</i>	Adams and Sanders, 2004 p203
Paradoxical feeling	<i>"I sometimes sit here, and I look at him in quiet moments...and I'm like, 'What happened? Where are you?'"</i>	Lindauer et al., 2016 p738

	<i>"I look at him sometimes and think the "he" I know is no longer there. Once in a while, there is a flash of the person he once was and then it is gone. This makes me sad. I would rather have him all here or all gone"</i>	Adams and Sanders, 2004 p203
Caregiving as a natural role	<i>"...you're taught this, you're programmed for it. You just step into the role...yeah, it's an easy thing to do."</i>	Lindauer et al., 2016 p737
Feeling rewarded	<i>"I am grateful to be able to care for her (mother -in-law) and treat this as end-of-life blessing for me. We need to be mindful of Allah's plan. Although I was busy caring for my mother-in-law, I still managed to obtain an A, maybe because she was silently praying for me in her heart. Taking care of her is my hereafter reward." (P4)</i>	Idura et al., 2018 p98
	<i>"I opened my first kindergarten in 2008, in 2009 I opened my second branch and the third in 2012. I felt that my success was a blessing as a result of caring for my parents. Allah makes things easier for us when we care for our parents. This has made me more enthusiastic" (P7)</i>	Idura et al., 2018 p98
	<i>"Allah has tested me but I believe He has provided me an advantage by paving the way for me to get a scholarship to pursue my Masters and PhD. All these were possible because I cared for my father." (P8)</i>	Idura et al., 2018 p98
Managing challenges through religion	<i>"I pray a lot and ask Him for guidance."</i>	Lindauer et al., 2016 p737
	<i>"I'm a Christian. Especially when it is stressful and emotional at that time, we pray to God. I feel at ease." (P3)</i>	Idura et al., 2018 p97

	<i>" My faith is the only thing now that gets me through. It is the only thing that I can depend on. God is the only one that I can count on..."</i>	Smith et al., 2001 p21-22
Unpreparedness for caregiving responsibilities and inadequate knowledge	<i>"3 to 4 years ago, me and my sister discovered something wrong with her (mother) when she started to tell funny story and started to forget many things. It took us 3 years before we brought her to hospital." (P3).</i>	Idura et al., 2018 p96
Grief	<i>'The first time my father didn't know me was the day our old relationship died. I was stunned at how hard I took this. He is in front of me and I can't ask him anything. He always was able to give me advice. It is a constant reality shock every day to still see him and not communicate. It's like being teased. He's here, but not.'</i>	Adams and Sanders, 2004 p203
What remains	<i>"...she can still remember some things...she still has good days" (Caregiver)</i>	Lindauer et al., 2016 p738
Hanging on	<i>"...I don't want to see him leave this earth at all."</i>	Lindauer et al., 2016 p737
	<i>"God willing...live to 100."</i>	Lindauer et al., 2016 p739
What is lost (lost personality)	<i>'I miss the togetherness that my husband and I had . . . I miss his caring for his family. He was fun to be around. Now he is not nice.'</i>	Adams and Sanders, 2004 p203
	<i>'Little things – memories – will suddenly appear and I'll become very sad. I have no one to go to the movies with anymore – We ran out to see every movie. I have a very</i>	Adams and Sanders, 2004 p203

	<i>hard time at the holidays – we enjoyed them so. The death of dreams is terrible.'</i>	
Maintaining control	<i>"... we have been married for 56 years.... now I have to help him with almost everything. At home, I have routines for everything. That is what works for me, but it is very tiring"</i>	Tretteteig et al., 2017 p450
Sending away/ failure to maintain control	<i>"... I think it's too cruel to send my wife to a nursing home. I feel guilty towards her and blame myself for having such thoughts...."</i>	Chan et al., 2010 p165
Guilt following placement in care facility	<i>"...I could have been more proactive... I just feel I wish I'd done more for him really. I just think he deserved better and I hope that guilt feeling... that I'll learn to live with that really." (ID12, daughter)</i>	Moore et al., 2017 p9
	<i>"First of all I am guilty about this, on the other hand I feel better off being on my own, as I can do what I want."</i>	De Silva and Curzio, 2009 p13
	<i>"I hate myself for agreeing with this move and I am guilty"</i>	De Silva and Curzio, 2009 p13
Fear of respite	<i>"it meant that this would be where she would end her days" (I4).</i>	Brunton et al., 2008 p352
Shared identity (of hardship and discrimination)	<i>"...if you look back in slavery days...all we had was each other to keep each other going. From young to old, we took care of everyone. I think that's what we had to do. We were there for the sick. We were there for the babies. We were there for the White people's babies...I think it's just the caring nature that's just in us, that just passed from generation to generation."</i>	Lindauer et al., 2016 p738

### Appendix 3: Information pack

#### Participant Invitation (by post-non-JDR)

Date:

Address:

Dear Sir/Madam,

Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.

My name is Charles James. I am a PhD student at the Faculty of Health and Medicine within Lancaster University. I am kindly requesting your participation in a research study titled above, which I am conducting. This is a research for academic award only and the purpose is to ask for your experience of caring for someone with a moderate to advanced dementia at home. The study is interested in finding out about those situations in which you know the right thing to do but feel powerless to act or make any changes.

If you decide to participate, I would like to visit you to conduct an interview which should last around an hour. If you would like me to interview you in another location other than your home, please let me know and we can both agree on a convenient place. A small contribution will be made towards your travel in this case. I have enclosed a Participant Information Sheet which gives more details about this study, and a reply slip with which you can let me know that you wish to participate. I look forward to hearing from you.

Thank you.

Yours faithfully,

Charles James PhD Student,  
Faculty of Health and Medicine, Lancaster University

**Email Contact (Using JDR)**

Date

Dear \_\_,

My name is Charles James and I am contacting you as your details have been matched on Join Dementia Research website as a potential participant for the study title **'Exploration of Informal Caregivers' Experience of Home-Based Care Provision for People Living with Moderate to Advanced Dementia'**

I understand from your profile on JDR website that you wish to be contacted by email and telephone. I have therefore attached a participant information sheet, an invitation letter and a reply slip which needs to be completed and returned to me at the address included.

Once I have received the reply slip, I will then call you to agree on a convenient place and date when we can meet for an interview.

I look forward to hearing from you soon.

Yours faithfully,

Charles James  
PhD Student  
Lancaster University

## **Participant information sheet (PIS)**

**Title:** Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.

### **Introduction**

My name is Charles James, and I am conducting this research as a student in the PhD programme at Lancaster University, United Kingdom.

### **What is the study about?**

The purpose of this study is to explore the stories of family carers and how would they describe their experience of caring at home for someone living with a moderate to advanced dementia.

### **How do I qualify to take part?**

You need to be able to speak and understand the English language, and be looking after a relative, family member or friend within a domestic home setting.

### **Why have I been approached?**

You have been approached because you have been identified as a person who helps to care for someone with dementia. This pack may have been given to you by a care agency, support group or similar who are helping with this research.

### **Do I have to take part?**

No. Participation is voluntary, and you can decide whether or not you wish to take part. You may also withdraw at any stage, either before or during the interview, and up to 2 weeks afterwards.

### **What will happen if I take part?**

Once you complete and send back the enclosed 'reply slip', I will contact you to arrange an interview at a time and place that suits you. If this place is not your home, you will be paid £10 for the cost of your travel, at the end of the interview. You will also have an opportunity to

discuss this research with me before you decide to take part. Before your interview, you will also be asked to sign a consent form, which will be fully explained to you.

### **How long is the interview?**

Most interviews are likely to last about an hour but should last no longer than 2 hours.

### **Where will I be interviewed?**

Most people choose to be interviewed at home. However, you can let me know if you would prefer to be interviewed somewhere else.

### **Will my data be identifiable?**

The information you provide is confidential, and your data will be stored securely. Only I and the study supervisors will have access to this data. After the interview, your data will be anonymised before being used.

### **Are there any risks?**

The risks in taking part in this study are likely to be low. However, if you experience any distress following participation, please let me know. You may also make use of the other contacts provided at the end of this sheet.

### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part.

### **Are there any incentives paid for participation?**

No. However, if we are unable to conduct the interview within your domestic home setting, then a small contribution of £10 will be made towards travelling cost to a different location of your choice. This will be paid at the end of the interview.

### **Confidentiality**

Please note that there are some limits to confidentiality. If what is said in the interview makes me think that you or someone else is at significant risk of harm, I will have to follow the necessary guidelines, and also speak to my supervisors about this. If possible, I will tell you if I have to do this.

### **What will happen to the results?**

The results will be summarised and reported in a thesis. It may also be submitted for publication in an academic or professional journal. The data may also be made available to other researchers for educational purposes.

### **Who has reviewed the project?**

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee and approved by the National Social Care Research Ethics Committee.

### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact me:

Name: Charles James, Faculty of Health and Medicine, Lancaster University, Bailrigg, Lancaster LA1 4YG Tel: 07885911473. Email: [c.james3@lancaster.ac.uk](mailto:c.james3@lancaster.ac.uk)

Or the research supervisors:

a) Professor Katherine Froggatt, Faculty of Health and Medicine, Lancaster University, Bailrigg, Lancaster LA1 4YG Tel: (0)1524 593308. Email: [k.froggatt@lancaster.ac.uk](mailto:k.froggatt@lancaster.ac.uk)

b) Professor Catherine Walshe, Faculty of Health and Medicine, Lancaster University, Bailrigg, Lancaster LA1 4YG Tel: (0)1524 510124. Email: [c.walshe@lancaster.ac.uk](mailto:c.walshe@lancaster.ac.uk)

### **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study, and do not want to speak to me directly, you can contact: Professor Nancy Preston (Director of Post Graduate Studies for the Division of Health Research), C051, C - Floor, Furness College, Lancaster University, Lancaster LA1 4YG. Tel: (01524) 592802. Email: [n.j.preston@lancaster.ac.uk](mailto:n.j.preston@lancaster.ac.uk)

If you wish to speak to someone outside of the Palliative Care Doctorate Programme, you may also contact: Professor Roger Pickup, Associate Dean for Research, Faculty of Health and Medicine (Division of Biomedical and Life Sciences), Lancaster University, Lancaster LA1 4YG Tel: +44 (0)1524 593746. Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)

### **Resources in the event of distress**

Should you feel distressed either as a result of taking part, or in the future, the following external resources may be of assistance:

a) Samaritans:

Local Address: 5 Northgate Business Park, Off Northgate Street, Bury St. Edmunds,  
Suffolk IP33 1HP. Tel: 01284 750 000 or 116 123

b) The Silver Line:

National Tel: 0800 4 70 80 90



### WHO CAN TAKE PART?

- Family carers currently caring for someone living at home with a diagnosis of dementia, or
- Family carers who have cared for someone with dementia who lived at home within the past 6 months

### ETHICAL APPROVAL

- **Sponsor:** Lancaster University
- **REC Ref:** 18/WM/0001

## DO YOU WANT TO TAKE PART IN A DEMENTIA RESEARCH STUDY?

### What is this study about?

We want to understand what it is like to look after someone in your home who has dementia. We are particularly interested in when you care for someone whose dementia is getting worse, and they might need help getting dressed or looking after themselves.

### Interested?

Interested participants can request a study pack from the person who gave you this flyer or runs this group. You could also request a pack directly from: Charles James (Researcher), C/0 Suite 6A Clocktower Mews, Exeter Road, Newmarket, Suffolk CB8 8LL. Email: [c.james3@lancaster.ac.uk](mailto:c.james3@lancaster.ac.uk) Tel: 0788 5911473

**Reply Slip**

**Title:** Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.

**Researcher:** Charles James

I have read the information sheet dated \_\_\_\_\_ for the above study and I am:

(a)  Interested in taking part. I understand that I will be contacted by the researcher who will explain the study to me and answer any questions I might have. I also understand that it will then be entirely my decision whether or not to join the study.

(b)  Not interested in taking part. I do not wish to be contacted about this study.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Tel No: \_\_\_\_\_

Email: \_\_\_\_\_

## Appendix 4: Eligibility Checklist

Inclusion criteria	Criterion met?	Comments	
Participant is ≥ 18 years of age		Participant Age:	Patient Age:
Participant is a family carer		Date of diagnosis (if available):	
Care is currently provided within domestic home		Length of time caring	
Care has been provided within domestic home in the last 6 months		Relationship:	Participant Gender:
<u>Additional notes</u>		Current location of care:	
		Home: <input type="checkbox"/>	
		Elsewhere: <input type="checkbox"/> (state where)	
		Employment status:	
Some exclusion criteria		Criteria met and documented?	
The carer is not a family carer lacks capacity to consent to participate has insufficient English language skills to participate in an interview			
Participant is:		Eligible <input type="checkbox"/>	Not Eligible <input type="checkbox"/>
Completed by		Charles James	Date: / /
Principal Investigator:		Professor Catherine Walshe	

## Appendix 5: Consent form

**Title:** Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.

**Researcher:** Charles James

Before you consent to take part in this study, I would like you to ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form, please feel free to ask. Thank you.

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask questions and had them answered.
3. I understand that my interview will be audio recorded and my details kept confidential.
4. I understand that audio recordings will be kept until the research project is completed.
5. I understand that my participation is voluntary and that I am free to withdraw by letting the researcher know that I do not wish to continue at any stage, either before or during the interview, and up to 2 weeks afterwards without giving any reason
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that any information I give will remain strictly confidential unless it is thought that there is a risk of harm to myself, or others, in which case the principal investigator may need to share this information with the research supervisors.
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.
11. I understand that I can request a summary of the study findings once published.
12. I understand that my data may be made available to other researchers for educational purposes.
13. I consent to take part in this study.

Participant's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Researcher's Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

**Step 1: Introduction**

- *Introduce yourself and thank the participant for consenting to take part in the study*
- *Remind the participant that interview will be securely recorded*
- *Remind the participant that they can request that the interview be paused or stopped at any time they feel unable to continue*

**Step 2: Setting the scene to initiate the start of interview**

- Ask a question such as: How has it been, caring for Y (substitute Y with a name)?

*Exploration of points raised from the initial question will be followed up with questions such as:*

- When did you realise you were providing care to Y?
- How did that make you feel?

*Establish some of the challenges faced in caring for 'Y' with questions such as:*

- Tell me about the things you have found challenging about caring for Y
- What particular aspects are challenging about that?
- What did you do about this challenging experience?
- How has it been for you in doing anything about this challenging experience?

*Explore things the participant has found helpful with questions such as:*

- Has anything made caring for Y become easier or harder?
- Is there anything you have found that is particularly helpful?

*Probe about the participants' expectations with questions such as:*

- Would you say this experience of caring for Y is what you had expected?

*Establish of particular occurrences where choices had to be made or were challenged with questions such as:*

- Would you say there are any aspects of caring for Y that had given you concerns but you carried on regardless?

*Establish of the effect on the participant with questions such as:*

- In what way have you been affected by this experience of caring for Y?
- Would you consider this experience particularly easier or more difficult because of your relationship with Y?

*Look forward to the future with questions such as:*

- What would you change if you could or what would you do differently?'

**Throughout the interview, some of the prompts below may also be useful in eliciting further details from participants:**

- *Can you tell me more about that?*
- *Why do you consider that important?*
- *Why did you say that?*
- *Would you advice other people in your shoes differently?*
- *Is there anything else you would like to tell me?*

### **Step 3: End the Interview**

- *Let the participant know the interview has come to an end*
- *Ask the participant if there is anything else they would like to say*
- *Re-assure the participant that their personal data and details would be safe*
- *Thank the participant and re-iterate that they can withdraw if they change their mind by letting the researcher know, up to 2 weeks after the interview.*

## Appendix 7 : Original transcript [participant A1]

[ID: A1] [Date:18/06/2018] [Duration: 60:26Mins]

### Introductions

CJ [Interviewer]: My name is Charles, Charles James, I am a student researcher from Lancaster University, and what we will be talking about today is about your experiences of looking after er... your wife...

A1 [Respondent]: yeah

CJ: I never asked for your wife's name...

A1: [mentions wife's name].

CJ: [mentions wife's name]. Ok

CJ: Erm... just your experiences of looking after [mentions wife's name], erm..especially you know in the home. So most of the references we would be making today and will be talking about will be more focused on the care within the home.

A1: Right OK

CJ: Rather than elsewhere.

A1: Yeah

CJ: Not that we are not interested in that as well but you know its majorly about what's happened.

A1: Yeah

CJ: How we've got to today and you know where were we and where are we now.

A1: Yeah.

CJ: OK Umm... urrrr the data will be recorded and then it's going to be transcribed later on. Umm... if at any time as we going along you feel like you don't want to carry on, you just tell me and I'll stop the recording...

A1: Right

CJ: ...and we'll stop the interview. We can also pause, or take a break, that's fine.

A1: Ok, yeah, no problem

## Interview Begins

### **Q.1. General perception of caregiving experience: from diagnosis to date**

CJ: Okay. Umm, the first thing I'm going to ask you please is for you to tell me...just give me a background about how [mentions wife's name] was diagnosed, and you know...

A1: I was just looking at ummm my catalogue...[gets out a few letters and searches through]...I don't remember these things, but she first went for an assessment in December 2010.

CJ. Right.

A1: Got my notes here and they said [clears throat]...they did the Addenbrookes cognitive exam and she scored 94 out of 100, which is normal for her age. But I mean we wouldn't have put her in for this if we didn't think something was wrong. So you know I'm convinced at that point there was the start of it you know but just memory loss and... you know things like that. She wasn't formally diagnosed until October 2012.

CJ: Two years afterwards

A1: A couple of years when was that... December yeah, sooo... ermm... [inhales]... yeah but it had a devastating effect on her when she was diagnosed, well both of us really [looks down for a while] but you know particularly [mentions wife's name]. She ermm... cos they did ask us when they did this test [sniffles]... umm do you wanna know umm... the results you know... you know... what, what our findings are umm....we both said oh yes, yes we wanna know but [swallows]... when they said she'd got dementia she just went to pieces, she couldn't handle it so she started to drink...yeah [draws in breath and looks down in thought] and uhh... I said she fell downstairs twice and finished in hospital over it yeaah. Sooo... in hindsight, we, I wouldn't have said yes [laughs] you know! Umm... yeah... and then ummm.... I've lost me train of thought now...

CJ: It's ok. So you feel that you would have preferred if she hadn't been told....

A1: Yeah and that what I was gonna say. Then a couple of years I dunno what might not have been a couple of years. Further down the line, at least a year, say. Ummm... they did another assessment... and they said umm... they have reassessed it and she's got mild cognitive impairment.

CJ. Right

A1: Far as I know that's just a stage

CJ: Yeah

A1: Of dementia, but we didn't know at the time, certainly [mentions wife's name] didn't know. And she just [clicks fingers loudly] changed like that. All the depression went away, she got on with her life, she was fine. So you know that was, that made a huge difference umm... and I'm wondering whether they actually, the doctor did that on purpose cos he knew what an effect it was having on her. Yeah... soo...

CJ: So would you say you found that change of diagnosis helpful a little bit in...

A1: Oh yeah, it helped her a lot, yeah and me really. I mean you got this real terrible weight and..., I mean we were in tears almost every day the pair of us, to start with. Uhh... in fact that er... of the whole of my experiences so far that was the very worst time when she was first diagnosed.

CJ: Right

A1: Yeah... mostly.... so umm... I'm trying to [coughs] think what happened then umm... I mean these things obviously happen in [clears throat] slow time really.

CJ: Yeah

A1: And that's a job to tell [pauses]... is she getting better? Or worse? Or what? You know it... it's very difficult you know and after three or four months you think she's not really any worse than she was before. But you know she is getting worse and I think as time goes on it's accelerating, I think. Yeah.

CJ: So you could tell the difference over time?

A1: Yeah... yeah... yeah

CJ: Ok

A1: I mean one of the first things we noticed apart from her memory was, if she... if she's sitting near you watching tv and she'd nod off

CJ: Right

A1: And then she'd wake up and she'd start talking to me in third person as if I was somebody she didn't know! [gestures with both hands] She'd talk to me about me you know I thought woah woah! I feel a bit freaky [chuckles] but she does that all the time now I've got used to that but er er [stammers] at the time that was quite scary [snifles]

CJ: Right

A1: But umm... and she was still driving, I can't remember when she packed up driving but she was driving for a long while and.... umm... and then I.... I dunno why she stopped now, o yes I do. She had her licence umm... had to have umm... the DVLA had to know about the condition.

CJ: Yeah

A1: So that she had to be checked regularly umm... or apply for a new licence at the end of I think every year or something like that [snifles].

CJ: Yes

A1: But umm... one day I... I said to her I don't remember you doing anything about your licence so we found her licence and it was about 4 months out of date [laughs] so so that's it you're not allowed to drive unless you apply for it again. So we applied for it again but I think we used the wrong form.

CJ: Right

A1: We used the ordinary form and it... it... it... just went on and cos the longer these delays went on, the more she got used to not driving and at that point I was at home cos I hadn't

been working... at that point I was home all the time so it weren't so much of a problem you know. But uhh... she did like driving cos that's what she used to do...she's done a few jobs but one of the jobs she kept going back to was parts delivery in the motor trade she used to drive at euro car parts and that sort of thing.

CJ: [Laughs briefly]... Oh right

A1: Yeah... [goes quiet and swallows]... and she used to do hundreds of miles a day!

CJ: Oh goodness!

A1: Just locally yeah, just amazing yeah... but like I...I was talking to some of her colleagues since she retired, she was having a few problems with her memory then. Umm... cos occasionally she'd forget a part, well you know [draws in breath]... umm... so then....even then you know something was going on.

CJ: So that was before she was formally diagnosed.

A1: She retired at 65 she could have retired at 60 but she wanted to keep going. She retired at 65 but she's 73 and so... so... it's eight years it's been going on really. Uhh...

CJ: Ok.

A1: Yeah... uhh... what else? and then umm... as it progressed, we started to... they uhh... social services I think it was social services got involved [clears throat] more and umm... it was decided that she should go to [mentions day centre]. You know to give her a bit of...bit of structure to her life I s'pose.

CJ: [mentions day centre] is the... that's the club down the town.

A1: Yeah where you met me.

CJ: Yes.

A1: And umm... she started off going one day she weren't very keen this time... but once she got to know everybody umm... she quite liked it and we gradually ramped it up till she was on four days a week.

CJ: Right

A1: Yeah...[looks away]

CJ: Ok. Did... did you find that helpful?

A1: Oh... enormously yeah, yeah. I couldn't have managed without the... er... these people. Yeah

CJ: Ok

A1: Cos the support you get from there is really important you know. Yeah

CJ: Yes

A1: I mean when I first went, when we went up in the carers' group, we all sat around the table and they were all talking about their problems and they... [draws in breath]...then I was aware that they were all looking at me! A1 & CJ [both laugh]

A1: And I don't do this [Laughs]. So I didn't go for some time after that, but I gradually got back into it. But now I know everybody, you know it's uhh... it's like a chat with your friends really, well they are your friends.

## **Q.2. Perception of being a caregiver**

CJ: Would you say you found it daunting to start with?

A1: Yeah...

CJ: Sharing...

A1: Yeah...

CJ: ...what's going on with...with...

A1: .... talking with everybody else in the group, people I didn't know, you know

CJ: ... talking with them.

A1: Yeah... I'm not the most outgoing person [laughs softly]. So umm... yeah... uhh... emm... what [clears throat] and then it got...cos I've never been able to help her... in the...in er...in the toilet clean her up, and things like that, she's never let me do that so umm....pauses] and then she got so she couldn't manage herself she was having accidents and things like that so then we started having the carers come in... emmm...[looks down] and then initially they were just coming in twice a day morning and evening, and then problem was on a... ummm... on a Friday when she didn't go to [mentions day centre] and the weekend, I got no support between morning and bedtime

CJ: Right

A1: You know, so that was getting difficult, so social services put another two visits on soo... for those three days we had four visits a day from social.. from um the carers.... And that was enormous help for me, I mean very often there weren't too much to do to her.

CJ: Yeah

A1: They come in to.. you know... really really brightened my life a bit to be honest [laughs]

CJ: But other times when they are not here you'll be responsible for all the care apart from the personal care?

A1: Yeah that's right, well see if ... if she got in a mess... big time she wouldn't let me help her I used to have to phone her daughter, come and help

CJ: Right

A1: And she lives at [mentions village name] which is I dunno 7 or 8 miles away soo... but then uhh... it all came to head over last Easter. [mentions wife's name] umm... had diarrheah in the middle of the night, bad diarrheah, and umm... she went in the toilet she wouldn't let me help her [pauses] at all [gestures with hands to stress] and she had er...she wore these pull ups you know... and they were all full of... crap you know [laughs] and she was... and I thought I... I can't leave her like that, she was wanting to walk round the house and go back to bed and all the rest of it... soo... umm... I had to call her daughter out in the end but I mean

she...she was still [inhales]...I... that's right she came that time and then later in the night this happened about three times in the night I had to keep calling her daughter out... but I mean it got so at one point where I had to... [frowns]... I had to forcibly cut this... pull up and I now know that you can tear em but umm I had to cut this thing off her you know... umm....poor old dog cos he got covered in poo as well you know [A1 & CJ laugh together]... and it all came to a head. So umm... her daughter said I'll phone, you know you need a break cos I was...you know I'd had enough. So umm... she got involved with social services and it was decided she was gonna have to go for respite. Well I know from talking to other people when they go to respite its nine times out of ten it's a one-way ticket... you know, which is what it proved to be soo... [pauses].She went over to Risby... she was er...s'posed to be there two weeks but she was there four weeks because I...I wern't happy with it because I was having to pay £335 a week top up.

CJ: Hmm

A1: Well, yeah... after a few years I was gonna be skint [laughs]... so I couldn't allow, I can't allow that I can't...I gotta live at the end of all this, you know. Soo... umm... social services er...said well, we'll look to see what hours there is. They came up with two or three, we went and we finished up going to Stowmarket but umm... uhhh... what's it called [mentions care home's name].

CJ: Right!

A1: Which is a Bupa run one, and there's no top up fees there.

CJ: Ah.

A1: I mean the only downside there far as I see there's not an en-suite but so what there's a toilet across the road and she's got a umm... a commode, which is more likely used to be honest, and there's not, I don't think there's much in the way of staff there, not so much as there was at [mentions village name]. Other than that I've got no complaints at all. One thing I do like about it I've never known it to smell.

CJ: What? the home?

A1: The home, cos some places I mean [mentions village name], one day I went in her room and you could cut the air with a knife... it was awful, but I've never known any of that.

CJ: Right

A1: So you know I'm quite pleased with that.

CJ: So would you say you found the external help outside of the home helpful as well?

A1: Yeah.. yeah.. yeah.. yeah.

CJ: You did? Ok. Thank you for that

A1: So that's umm... but I mean when she was at home very often she wouldn't go to bed. And she'd be up all night..., like I've got to get some sleep, so I made the house safe..., and sometimes I used to pull the the the light switches, pull the fuses out so you couldn't...cos she used to put all the lights on, every single light in the house was on. But uhh... I got LED lights which made it a bit cheaper, still they're all on, you know. And then sometimes I'd come down in the morning and she's still awake and she you could hear her talking all night

long cos you can hear through the floors here. So umm... but the funny thing is when she'd been like that, she was as good as gold the next day....no problem at all... but... then you find the next day she was dead on her feet by tea time you know

CJ: Yes

A1: So she'd go to bed early... and when she went to bed she'd sleep, she was fine.

CJ: She sleeps right through

A1: She sleeps all the way through and then when she get up she's really awful [inhales]... couldn't do anything with her [pauses]... but umm...

CJ: Ok

A1: And...and that's still going on in the home. They're having...they're having problems [chuckles] with her the last few days but uhh... The doctor did give her some er... sleeping pills but he said they're addictive so don't give umm... to her unless you absolutely have to so I think there's only about nine in a packet I wasn't giving her any more than about one in a month. You know just when she was really bad... but umm... I think they're giving her more than that where she is now [looks away].

CJ: Right ok.

A1: Hmm... in fact yesterday they couldn't do anything with her, they managed to get her top on...but they say they couldn't clean her or put...put anything on her bottom half... she wouldn't do anything... wouldn't let um wash, wouldn't let um comb her hair..., swearing at um.... so it s'posed to be getting emm..I think the doctor's gonna go and have a look at her. She gets, keeps...keeps getting water infection that's another thing and when she's got a water infection that's it you can't do anything with her[inhales]... yeah...

CJ: Ok. So... what I understand by what you've said is you know, obviously you've had to care for her in between the carers coming in and...

A1: Yeah...

CJ: ...the help from uhh the daughter and other people.

A1: Yeah...

CJ: So how would you say that the caring aspect you know the ones that you had to do, how would you describe that? How was it?

A1: Well...I don't have a problem with it... I mean I've... housework I'm not terribly good at, but [both laugh]...I now know how to use a washing machine

CJ: Yes

A1: And I was...[mentions wife's name] was always a very good cook and that was one of her hobbies.

CJ: Right

A1: And I wasn't allowed In the kitchen only to wash up ...so but it got to the point where she couldn't manage it anymore, so I took over, so I've been cooking for two or three years now... so you know I cook good plenty enough for me [both laugh]... but when she was here I used

to cook proper meals... but since she's been in the home which is like 8 weeks now, sometimes I just have a sandwich I, you know..[A1 inhales]... I can cook if I can be bothered [A1 laughs]. I haven't got any thinner though [both laugh]. I did to start with but then when I was all stressed up over it, it was all horrible... come in the house, an empty house is...is awful you know... it's not nice at all[voice drops and A1 looks away]...yeah. I mean I've been divorced... nearly thirty years ago now... and my wife left... and it's...it's not the same, you know...this is more of a sadness to it now ... whereas, then I was angry really you know... [laughs and inhales sharply]...er...but umm... if I hadn't got me dog I'd be lost...you know...and I got some good friends as well...but it's a big difference... yeah..[long pause]. Some people bottle this stuff up don't they and don't tell anybody and I think that's bad you gotta talk to people, yeah... and you find out who your friends are as well. That's the other thing.

CJ: That's right

A1: Some of them just disappear.

CJ: Yes

A1: Yeah but uhh...[fades off]

CJ: So you feel talking about the emotions that's really helpful as well.

A1: Yeah yeah yeah yeah.

CJ: So coming into an empty house is what you would describe that as the worst part of everything.

A1: Really yeah yeah yeah, even now I leave the radio on or leaving the tv sometimes... and the lights, so when I come in, it feels like there's somebody here. You know

CJ: OK

A1: But another thing is see [mentions wife's name] umm... she was always very... house proud if you like [pain in voice detected/feeling of loss undertone?], and she was spick and span... you know... well I've never been quite that bad but you know [laughs], she got so that umm... she used to take things out and fold em put... every drawer and cupboard in this house has got everything in it. You know what I mean [laughs]. You don't know what's in any drawer or you didn't But I'm gradually sorting these out but see that's that... can be pretty gut wrenching things when you find photographs and thing like that [looks away]

CJ: Yes... and that brings it all back to you.

A1: Yeah yeah yeah

CJ: Ok

A1: Another problem I had, I dunno why I'm laughing [exhales]..., another problem I had... about two three years ago, I was clearing out cupboard upstairs and I found a box of paperwork... and inside it uhh... was all bank statements and stuff like that. And I found that [mentions wife's name] er.. owed money...

CJ: Right

A1: And I didn't know anything about this cos we kept our finances separate you know, cos she was working and I was working... umm... but when I got to the bottom of it, she owed a hell of a lot of money.

CJ: Right.

A1: Umm... so I had to get that sorted out as well and I got in touch with an organisation called the C.A.P (Christians Against Poverty)I don't know if you know of it, they've been very helpful but what we've finished up doing was... all her state pension

CJ: Right

A1: I had to pay towards these debts.

CJ: Right

A1: And she's been paying them off over two years now..., but she's paid half of it but there's like, you know... 28 thousand quid.

CJ: Still left?

A1: That's how much she owed... so there's about half of that left now...

CJ: Ok

A1: ...so they trying to get it written off I dunno whether they are having much success with that but we'll see what happens... yeah. So that was a hell of a shock that was. Cos I knew nothing about it... and she...don't know, she don't know anything about it either now. Cos... what she was doing was getting the correspondence and anything that came in to do with her she was just tearing it up. So although she didn't, I dunno how much she owed to start with but it certainly wasn't that much that's just been adding...

CJ: Interest?

A1: ... interest on...selling the debts on and the rest of it.

A1: soo...umm... that was a right real real shock that was, in fact if she hadn't have had dementia [inhales] it would probably have finished us... finish us as a couple I reckon. You know, she'd have been down the road. So that left a nasty taste in my mouth you know.

CJ: Yeah

A1: So yeah it's not been easy! [Laughs]

CJ: It's not been easy...ok all right. Umm...

A1: ...this is all credit cards

CJ: Credit cards, right.

A1: And store cards, nothing... I can say nothing serious you know what I mean, secondary debt is what they call it [Clears throat loudly]

CJ: Ok. Are you all right to carry on?

A1: Yeah.

CJ: Yeah? Thank you, umm... after the diagnosis, and you know through the experience uhh... going on you know all the external help you were getting, at what point did you discover or realise that you were actually a carer for [mentions wife's name]?

A1: Uhhh... I 'spose when I retired [laughs]

CJ: Right

A1: So I've been retired umm... four years I think it is this year ... or is it five, I can't remember now... but yeah cos I did, I retired when I was 67 I did an extra couple of years.

CJ: Right

A1: [pauses] but family kept saying you really ought to be here, you know mum needs you here, so I thought right [inhales]. Then the chance for voluntary redundancy came up so I said yes, I'm having it [laughs]... that was quite fortuitous. Yeah...

CJ: Yes ok... and how did you find that realisation at the time that you are now a carer?

A1: I don't know I mean you think you retire and you think we'll be able to [inhales sharply]... you now plenty of money and you'll go on holidays and all the rest of it... and none of that happened I mean I haven't had a holiday since I retired. So uhh... I don't think at any point I suddenly realised I was a carer it's just something that grows on ya you know. When you have to start filling in forms saying you're a carer you know [laughs]...that sort of thing

CJ: Yes

A1: When you gotta apply for... I forgotten what it's called now [long pause]... the carers benefit. What's it called, I can't think of it now. I dunno.

CJ: I think I have a little understanding of the process, so yeah I do understand.

A1: Attendants allowance... and they came and helped me fill the forms in actually, see this is another thing all these different agencies, I was very confused as to who was who, you know I mean you got NHS, you got umm... umm... what's it called... Alzheimer's society all those, they all seem to talk to each other and share these different roles.

CJ: Could you explain that a little bit further.

A1: Social services, to me, I weren't hundred percent sure who they are or how they all integrated.

CJ: Right.

A1: You know how I mean well I think there I don't know. I was a bit confused to start with about how who to turn to for various things. You know but they seem to sort itself out in the end.

CJ: Was it the process that was confusing or...

A1: Yeah well there wont a process it just sort of happened.

CJ: Right.

A1: Yeah.

CJ: Ok ok.

A1: Yeah well I purposely didn't dig into what was gonna happen cos I didn't really wanna go there if I'm honest [laughs] especially dealing with care home stuff like that you know. I been doing a bit of reading up on that finding out what you could/couldn't do. How much money you were allowed what's it gonna cost ya. Like it's stressful enough without having to deal with all that.

CJ: and how did that make you feel at the time?

A1: Oh I was really stressed yeah yeah yeah [fades] You get to the point were you just put your loved one away as it were then suddenly you gotta start figuring out how you gotta pay for it all. You know cos if you got more than 24,250 I think it is in the bank you don't get any help at all.

CJ: Right.

A1: So I had to make sure that [mentions wife's name] didn't have that well she hasn't cos she's paying her debts so. [Laughs] If she hadn't been if she'd had that much money then you know don't get any help whatsoever, you're on your own.

CJ: And you found that quite stressful?

A1: Oh yeah yeah yeah. [Very quietly] yeah if you're having to pay a thousand pound a week that's stressful to anybody.

### **Q.3. Account of caregiving challenges**

CJ: Absolutely yeah ok ok. So umm what part of the caring for [mentions wife's name] would you say, I mean apart for the sorting out, going into how to find out about going into a care home having external help coming to help you out, What other aspects did you find challenging and what did you do about those challenges.

A1: Just dealing with her on a day to day basis you know how she was. Umm she could be quite verbally aggressive not physically.

CJ: Right

A1: Running me down all the time.

CJ: Right

A1: Your useless you don't do anything! You don't do this you don't do that you know. Oh some of umm I didn't you know yeah.

CJ: And how did that make you feel at the time?

A1: Well it makes you feel pretty low obviously you know, but after a while you get to realise that this is just a condition that she's got and you tend to, it goes over your head a bit but you know it's still there. It doesn't have no effect if you see what I mean.

CJ: Yes

A1: Yeah

CJ: So how did you deal with that situation when you felt low?

A1: How did I deal with it? I used to go out and get in my Morgan sports car and go for a thrash!

[Both laugh]

A1: When I came back I felt a lot better.

CJ: Excellent

A1: [Laughing] Yeah you gotta have something to you know something to look forward to and.

CJ: Yes.

A1: And I brought that two years before I retired and that's something I've always wanted!

CJ: Right, so you found that outlet very helpful something outside the a little bit to help you concentrate?

A1: I gotta I've got a workshop I mean it's not very big but I've got uhh I used to be a design engineer.

CJ: Right

A1: But I finished up as a design engineer, most of my working life I was actually manufacturing. Which is Engineering, soo... I say two thirds of my working life I was making parts that other people designed I like making stuff and then the last third I was designing stuff for other people to make so I never saw that. [they laugh] So now I can I've got a laid and a millin machine out there so I've got I can keep my skills.

CJ: Yes

A1: Going you know what I mean

CJ: Yes

A1: and I can make what I want. So there that's what I do.

CJ: And you and obviously you're still doing that now?

A1: Yeah I can make parts for my friends got classic cars and stuff like that. I make.... All sorts of bits and pieces.

CJ: How does that make you feel in yourself?

A1: Well it makes you feel better about yourself don't ya cos otherwise I've spent what I left school at 15 finished at 67 all that experience when you retire for a lot of people it's gone. It's a waste!

CJ: Yes

A1: You know what I mean, I mean the last ten years I was using umm I was using a cat system to design things in 3D.

CJ: Right

A1: And uhh which I quite enjoyed like I say that's all gone now. Well it's not all gone it's still there but it's getting rusty cos I can't afford the software to to to do that anymore.

CJ: Of course.

A1: That's industrial stuff, thousands of pounds a seat you know.

CJ: Yes CAD yes I've seen that used once or twice and I didn't have a clue what they were doing.

A1: No

CJ: [Laughs] I didn't

A1: Its interesting really interesting stuff that it really is. See if it hadn't have been for [mentions wife's name] I would have gone and got a different job when I retired.

CJ: Would you have preferred to be working and getting paid?

A1: Yeah yeah

CJ: Was that the plan you had before retiring?

A1: No no it wasn't a plan you know just none of this was planned really other than working extra years to get my pension up a bit.

CJ: Right right

A1: Yeah you know I don't need financially I don't need to work but I like keeping busy.

CJ: Yeah so is there anything else you found helpful apart from driving?

A1: [Laughs] Well I might have a glass of whisky occasionally! [both laugh] Yeah but umm ohh I'd say having the carers in you know apart from the care aspect that they did for [mentions wife's name]. It was nice having somebody in to talk to you know. Uhh I really missed them when she went in the home yeah but uhh yeah

CJ: have you kept in touch with them at all?

A1: One of them phoned me back to find out how [mentions wife's name] was and I was really touched by that yeah but other than that they just disappeared don't they [laughs] yeah [coughs].

CJ: Okay ok are you alright to carry on?

A1: Yeah yeah I'm fine.

#### **Q.4. Account of caregiving expectations**

CJ: Umm I'm going to ask you about anything that surprised you over the time you were caring for [mentions wife's name] was there anything that you weren't expecting through the progression was there anything at all?

A1: No I don't think so no because I say you are expecting because it happened so slowly you know. But I didn't from but I didn't at day one go and say to myself I wanna know what

how this disease can progress what problems I'm gonna have. I can have let them happen when I happen you know got enough to worry about without doing that perhaps it's a bit of a head in the sand view but there you go that's me.

CJ: So you preferred not to know how things were gonna go?

A1: Well I did yeah [laughs]

CJ: Right would you have felt better if you had known or would you have felt.

A1: No I would have felt worse yeah. I did what was right for me yeah.

CJ: Right ok ok ok

A1: She could be a bit difficult and then another day she's really nice you know so yeah. I mean she used to take the dog for a walk 3 times a day.

CJ: Yes

A1: And that dropped off you know I got so I didn't like Letting her out on her own she used to go up town every day you know when she retired just get on the bus and go up it's only about 4 miles.

CJ: Yes

A1: And go do a bit shopping and then come back because that's what she's used to doing she used to go out to work every day you no she didn't wanna be stuck in the house.

CJ: Yes and she carried on.

A1: Yeah yeah yeah. I mean anything I used to notice when she'd go come home she would always have a pocket or a purse bulging with change and then I realised what it was. She couldn't work out the change on the money.

CJ: Right

A1: so she used to give a note for everything buy everything with she'd pay with a note.

CJ: Right

A1: So she's have all this change building up [laughs]

CJ: [laughs]

A1: Couple of times she went on a walkabout, one time I got she was downstairs, and I was having a shower I said I'm just gonna have a shower and when I got out she'd gone so I thought

CJ: She gone out of the house?

A1: Yes she gone out the house so I wandered round couldn't find so I thought I'd better get me bike out got that out the garage and cycled around the villages I was just get my bike out and there Land Rover pulled up [mentions wife's name] got out the passenger door

CJ: Okay

A1: And off it went and I later found out that [mentions wife's name] was the other side of the about mile or so off the road and in the sticks and like and this lady who luckily knew who she was umm picked her up and brought her back home again and then later and I spoke to this lady later an [mentions wife's name] was saying to her do ya know my husband's got dementia you know laughs so and that was that was the time when she cos she wouldn't except that she's got dementia.

CJ: Right.

A1: So for a long long time we didn't even dare mention it you know, but that that was interesting you know that point she said I got dementia laughs perhaps I have oh dear.

CJ: That's interesting that's interesting that she had that view of what's going on but it was reversed that's interesting.

A1: Yeah yeah yeah

CJ: Did that make you feel that make you feel?

A1: I thought it was funny!

CJ: You thought it was funny?

A1: Yeah yeah

CJ: Ok ok

A1: She went missing uptown as well

CJ: Sorry?

A1: She went missing uptown once I when she was a [mentions day centre] I took her to the dentist in the town.

CJ: Right

A1: I don't if you know Bury do you?

CJ: I know bury a bit.

A1: Well with parked at [mentions location name].

CJ: Yes I no [mentions location name]

A1: Well the dentist is over the road.

CJ: Yes!

A1: So I said stay in the car I will just go and pay you know for the car park so I went which is just around the corner 50 feet away probably. Went around the corner put the money in you know when I came back [mentions wife's name] had gone. I couldn't I walked around the car park couldn't see her anywhere, I thought well maybe she's gone into the dentist because she must known where it was and they hadn't seen now I walked round Waitrose and they hadn't seen her she wasn't in Halfords so I thought I'd better do something about this so I phoned the police and ummm they they put out a description to the PCSO I think. They asked me to wait outside of Halfords which I did and about half an hour later police car pulled

in just as they pulled in I spotted her about 50 yards away, she was walking along looking a bit confused you know. So I went and grabbed but you know I didn't know where she'd been but uhhh had to you know keep an eye on her after that yeah.

CJ: And how did that experience make you feel, I mean it wasn't the first time?

A1: I mean I thought someone will find her you know [laughs]

CJ: Okay.

A1: I mean I was worried that not that overly worried I mean her daughter was very worried.

CJ: Yes yeah.

A1: I mean she can't be that far away.

#### **Q.5. Account of choice making**

CJ: Ok ok. Okay umm did you have any concerns around the care that you said about her going missing a few times. Did you have any concerns at any points but you just carried on regardless

A1: Now know if there is a problem I'd do something about it. I got so I would lock the gates so she could get in the garden but not outside.

CJ: Right.

A1: But umm I was told I shouldn't lock her in because I was infringing her what was it human rights or whatever it was!

CJ: Yes

A1: She got a right go at getting run over their she, it was ridiculous gotta be sensible don't ya you know and the gas cooker couldn't I couldn't switch the gas off cos its gas central heating so I I drilled all the gas knobs

CJ: Yeah

A1: On the front an made a rod with a little locking collar on the end that you use with a little Allen key so that that was that made that safe

CJ: Right

A1: So the electric lights pulled some of the fuses out left some of them obviously but um she'd use and sugar anything sweet she would sit in the jar of jam so that was that towards the end that was starting to cause a little bit of a problem.

CJ: Right sweet tooth

A1: Yeah yeah she was a really sweet tooth so I mean that was the same point as she needed the care home so that didn't that wasn't a problem any more so yeah.

CJ: Right okay okay.

A1: Bit of a rollercoaster really I mean we're not there yet but.

CJ: Still ongoing!

A1: Yeah!

CJ: Ok Alright.

#### **Q.6. Account of the effect of caregiving**

A1: But I do feel more distance between us you know because I'm not with her all the time now you know I'm getting some of my life back but umm it does make you feel you know

CJ: What effect has that had on you the realisation that there's a bit of distance

A1: Yeah I dunno mixed feelings really uhh umm I can't get on with my life cos I'm still married [laughs] Do you know what I mean. Not that I particularly want to at the moment but there you go!

CJ: Yeah okay.

A1: Life's like that in my experience jogging along and every now and then you get a kick in the nuts that's what this was yeah!

CJ: That's true. So personally, I know you've just talked about you know uhh umm obviously you're still married and you can't get on with your life is a feeling you have how would you say it's affected you as a person.

A1: I'm it's made me more tolerant.

CJ: Right.

A1: Cos initially I wouldn't do with it you know I used to get angry you know. One time she she got up in the middle of the night because we never used to have the lights on she got up in the middle of the night I could hear her rummaging about what was she doing so I put the light on and we got a waste paper basket in the corner of the bedroom.

CJ: Yes.

A1: And she was weeing in it, she's sitting on it cos she thought it was the toilet.

CJ: Oh right.

A1: She did that once on the way to the toilet.

A1: Another time she did it sitting on a chair in the bedroom.

CJ: Right

A1: That really freaked me out cos I didn't like that at all.

CJ: Yeah

A1: But then you get over it I figured out you know she's getting confused as to where she is thas so what I learned is I left the bathroom light on and the door cracked open cos it's only next to the bedroom.

CJ: Yes.

A1: And umm an bought one of these little lights that you plug-in you know.

CJ: Oh right

A1: A nightlight left that on didn't have any problems like that anymore because she knew where she was going you know soo.

CJ: So you became tolerant and you found ways to deal with.

A1: I like to think I'm tolerant [laughs] maybe I haven't (laughs). You have to see the funny side of it as well that the other thing is not all it's not all miserable you know.

CJ: Yes

A1: There are funny sides about it but uhh yeah.

CJ: Hmm.

A1: And the neighbours have been good that's a thing got a couple of neighbours and they umm cos they've seen the progression as well.

CJ: Right.

A1: But they they were quite tolerant even though [mentions wife's name] used to be quite abusive to some of them

CJ: Right

A1: The lady that used to live just up there [mentions wife's name] would tell her to F off and all the rest of of you know.

CJ: Oh right.

A1: Yeah but towards the end towards the latter part the lady over there who she quite liked she turned on [laughs]

CJ: But they still came/carried on.

A1: Yeah they still carried on coming cos they realised you know.

CJ: Of course yeah

A1: next time she'll see as she throw her arms around her you know is just how things are you know yeah.

CJ: Yeah ok

A1: Yeah the lady over the roads her husband died two Christmases ago.

CJ: Oh right

A1: And she gets very lonely so she used to phone [mentions wife's name] up every other day and now she phones me [laughs].

CJ: And how do you find that people relying on you at this particular time

A1: I don't mind I don't.

CJ: You don't mind?

A1: No...that's pretty rotten being on your own that's why they're like that both of them live on their own.

CJ: So you understand there situation?

A1: Yeah I think so yeah.

CJ: Would that be because you've been there yourself you know...

A1: Yeah exactly.

CJ: Right, that's interesting I find that interesting that you can see where other people are coming from because you've kind of been in their shoes.

A1: That's it yeah.

CJ: Right Yeah okay.

A1: I mean the one that's got dementia or I think she do she will come up to me I mean I tolerate her whereas other neighbours they don't they get annoyed with her you know I mean.

CJ: Right

A1: But are she'll come in and she'll... sometimes I get a bit of shopping for her, I'll take it round and I'll say here's your shopping she says right how much is that £2.50 or whatever it was and she give me the £2.50 and I'll say right better go get my tea or whatever it is and she'll say right do I owe you any money I say no you've paid me. I mean I'll sit at home and they'll be a tap on the door "I think I might owe you some money." No you don't you've paid me you know [laughs]. So there you go.

CJ: Right so she's on her own?

A1: she's on her own but she's been on her own all along bless her and she's going blind now as well that doesn't help so there's always someone in a worse.. worse off position than yourself if you look around yeah.

CJ: do you... is that the view you've always held or something that just?

A1: Yeah I think so but it's just reinforced it really!

CJ: It's reinforced it.

A1: Hmm

CJ: Does that comfort you in any way knowing that?

A1: Convert me??

CJ: Comfort you.

A1: Does that old does that comfort me, probably a little bit yeah but there you go.

CJ: Right ok right we're coming to the end of the questions and you know going through this thank you for your time.

A1: One thing I just thought of when I first, when [mentions wife's name] was first umm diagnosed umm I went on a carers course six or twelve weeks or something over at Needham market umm.

CJ: Was that through the council?

A1: Umm I forget I forget how I got involved in it now it could have been yeah it wasn't the council it was I think Suffolk family carers.

CJ: Right Yes.

A1: But at that point anybody talking about their problems about their partners or the people they cared for and [mentions wife's name] was still driving she hadn't got we weren't far enough down the road you know I mean so I felt a bit of a fraud being there you know I mean?

Both Laugh

A1: So I don't think it did me any good really going there.

#### **Q.7. Account of what has been helpful**

CJ: What going for the course?

A1: Cos all I came away was knowing what the problems could be yeah.

CJ: Was that enlightening for you to see other people were going through?

A1: Yeah yeah it was actually.

CJ: would you say that helped you along over this time?

A1: I don't know if that helped at all to be honest, it was too early on really yeah I as far as I was concerned at that point I wasn't a carer cos I was at work then as I say [mentions wife's name] was still driving so it was really early on you know but anyway yeah..

CJ: Ok ok umm would you say that everything you've described today you know in this discussion would you say the experience of it all has been made more difficult or not because of your relationship with [mentions wife's name] may be in other words if she was somebody else that wasn't your wife?

A1: Yeah I mean

CJ: how would you have found that how would you describe that?

A1: I do know I think you more tolerant of of the person you love aren't you or you should be yeah I don't know.

#### **Q.8. Account of future plans**

CJ: Yeah okay okay. Is there anything you would change, or anything you would have done differently?

A1: I don't think I don't think so I mean she tried all these various medications I think there are four aren't there and I mean she tried those.

CJ: Yes.

A1: And all of them upset her.

CJ: Right.

A1: Well well well she said they did maybe they didn't you know I don't know [laughs] no I think

CJ: You would have done things

A1: I don't think I would have done anything differently no uhhh perhaps kept my temper a bit a bit early on yeah. But again [mentions day centre] have been really good in that respect you know.

CJ: Do you still find them helpful now

A1: Yeah even now yeah.

CJ: Even though she's not at home any more?

A1: That's right this still being helpful. Yeah

CJ: Ok ok what would you say you draw from their support now that is helping you to carry on even though..

A1: Well I mean there are people that carers that go there the carers group who are further advanced than me if you like put it that way you know umm there's one chap there his wife died you know he still comes see that's good to talk to him because you know he's had problems that I haven't seen yet you know.

CJ: Right

A1: Yeah so umm

CJ: You find that relationship valuable to maintain

A1: Yeah yeah yeah and it's just a matter to get out and to meet people that's good in itself. [clears throat] yeah.

CJ: Okay okay all right that's been great talking to you, hope I haven't taken too much of your time [laughs]

A1: You haven't been here that long have ya.

CJ: Is there anything else you'd like to tell me all in all is there anything else maybe what's the what's the care like now uhh what are your thoughts now she's no longer in the house.

A1: Well I don't think she's getting the care isn't as it was when she was at home. She was clean tidy and properly dressed but now you know she'll be sitting about with no knickers on for a while because she won't let them help her and things like that in her room you know.

CJ: Yeah

A1: But then you know she's getting worse she's gonna get worse.

CJ: And how does that make you feel just knowing that that's what's going on.

A1: [pauses] Well I don't know cos she probably wouldn't have let me do it either so you know [laughs] it's the best of a bad job really but uhhh yeah. But she she. I mean she's quite apt she'll take her knickers off in the common room there you know things like that you know there's no she doesn't know what she's doing you know it doesn't upset her cos its not the same person really. You know but uhh that's it because the person you know has gone really she's not the [mentions wife's name] I knew years ago you know not at all that's you know. I've got some photographs show you a few photos.

CJ: Yes please

A1: I've got hundreds of photographs on my computer that's one of the day she came home for when she finished work her last day at work.

CJ: Right

A1: so that would have been when she very first had slight problems.

CJ: Yes

A1: Got all sorts in here let me see for a later one. I haven't got a later one. Now this is that's her friend.

CJ: It looks like her sister!

A1: I know she's been a really good friend she goes and sees every day.. not every day every week.

CJ: Yeah!

A1: That's about 10 years ago as well. I I haven't got any I should have got some to compare with really.

CJ: (Laughs) Right and that's the two of you together

A1: and that was our six years birthday that was in Rick Stines restaurant in Padstow do know it.

CJ: I've heard of it.

A1: He's a celebrity chef ain't he.

CJ: How long ago was this?

A1: Well that's uhh 14 years ago.

CJ: 14 Years ago

A1: But I mean you've never met have you?

CJ: No

A1: she weighs about seven stone now she was fairly well-padded at one point.

CJ: Right

A1: That's a nice one I like that one.

CJ: Do you take comfort in seeing these pictures?

A1: Yeah I haven't got got any really nice pictures of her but there on there somewhere. Where's the other one? [shuffles about while tutting for a while]. This is a she was sitting there she had an ice cream.

CJ: Oh right ha ha ha

A1: That's still loading

A1: I suppose that's taken out from the cloud innit.

CJ: Yes

A1: Never known it do that before [laughs] Ohh

CJ: Right that's a video.

A1: I reckon this is getting full up.

CJ: Would you say you find looking at these pictures and videos especially

A1: Yeah

CJ: You find them very very useful for to look at from time to time?

A1: Yeah I mean you see she's not what she was there really.

CJ: Yes Yes.

A1: That's my granddaughters

CJ: Oh right how old are they?

A1: Look ones five and one's three that couple of weeks ago I had them to myself all day long I took out for the day it was a bit daunting that my daughter couldn't find anyone to look after them I thought I'd give it a go and I thought as I done the right thing here and I had a lovely day with them.

Both Laugh

A1: That's [mentions wife's name] sitting on the sofa [laughs]

CJ: That's her waving

A1: An that one That's my nosy neighbour.

CJ: Oh right

A1: Where's the other one I had on of her looking through the garage door somewhere. I dunno where that is. That one [laughs] very nice that! Oh go away [to computer] there it is that's a nice one I thought.

CJ: Ohh yes.

A1: See that was

CJ: Is that out here?

A1: See that was August 15 so that was two years no three years ago now innit. Yeah there you go.

CJ: That's great. So again I'm grateful thank you for your time umm

A1: Have you got your coffee

CJ: yes I'll have my coffee now.

A1: Do you want me to stick it in the microwave or make you another one?

CJ: No it's alright.

A1: you sure you sure?

CJ: yeah I don't mind cold coffee but umm it's been great talking to really really great and I thank you for your time

A1: Its all right

CJ: If you have any other questions or there's anything else you'd like me to know even if you just remember anything else you know you can always let me know you've got my telephone number as well just if anything comes up and anything crops up and you suddenly just remember something I would always listen definitely and I don't even mind coming back to listen to you know anything that..

CJ: Right I'm gonna turn this off now. Thank you very much.

[Recording ends]

## Appendix 8 : Restored transcript [participant A1]

[ID: A1] [Date: 18/06/2018] [Duration: 60:26Mins]

### Q.1. General perception of caregiving experience: from diagnosis to date

1. A1: I was just looking at umm... my catalogue [gets out a few letters and searches through]...I don't remember these things, but she first went for an assessment in December 2010.
2. A1: Got my notes here and they said [clears throat]...they did the Addenbrookes cognitive exam and she scored 94 out of 100, which is normal for her age. But I mean we wouldn't have put her in for this if we didn't think something was wrong. So you know I'm convinced at that point there was the start of it you know but just memory loss and... you know things like that. She wasn't formally diagnosed until October 2012.
3. A1: A couple of years when was that... December yeah, sooo... ermm... [inhales]... yeah but it had a devastating effect on her when she was diagnosed, well both of us really [looks down for a while] but you know particularly [mentions wife's name]. She ermm... cos they did ask us when they did this test [sniffles]... umm do you wanna know umm... the results you know... you know... what, what our findings are umm....we both said oh yes, yes we wanna know but [swallows]... when they said she'd got dementia she just went to pieces, she couldn't handle it so she started to drink...yeah [draws in breath and looks down in thought] and uhh... I said she fell downstairs twice and finished in hospital over it yeaah. Sooo... in hindsight, we, I wouldn't have said yes [laughs] you know! Umm... yeah... and then ummm.... I've lost me train of thought now...
4. A1: Yeah and that what I was gonna say. Then a couple of years I dunno what might not have been a couple of years. Further down the line, at least a year, say. Ummm...

they did another assessment... and they said umm... they have reassessed it and she's got mild cognitive impairment.

5. A1: Far as I know that's just a stage
6. A1: Of dementia, but we didn't know at the time, certainly [mentions wife's name] didn't know. And she just [clicks fingers loudly] changed like that. All the depression went away, she got on with her life, she was fine. So you know that was, that made a huge difference umm... and I'm wondering whether they actually, the doctor did that on purpose cos he knew what an effect it was having on her. Yeah... soo...
7. A1: Oh yeah, it helped her a lot, yeah and me really. I mean you got this real terrible weight and..., I mean we were in tears almost every day the pair of us, to start with. Uhh... in fact that er... of the whole of my experiences so far that was the very worst time when she was first diagnosed.
8. A1: Yeah... mostly.... so umm... I'm trying to [coughs] think what happened then umm... I mean these things obviously happen in [clears throat] slow time really.
9. A1: And that's a job to tell [pauses]... is she getting better? Or worse? Or what? You know it... it's very difficult you know and after three or four months you think she's not really any worse than she was before. But you know she is getting worse and I think as time goes on it's accelerating, I think. Yeah.
10. A1: Yeah... yeah... yeah
11. A1: I mean one of the first things we noticed apart from her memory was, if she... if she's sitting near you watching tv and she'd nod off
12. A1: And then she'd wake up and she'd start talking to me in third person as if I was somebody she didn't know![gestures with both hands] She'd talk to me about me you know I thought woah woah! I feel a bit freaky [chuckles] but she does that all the time now I've got used to that but er er [stammers]at the time that was quite scary [snifles]

13. A1: But umm... and she was still driving, I can't remember when she packed up driving but she was driving for a long while and.... umm... and then I.... I dunno why she stopped now, o yes I do. She had her licence umm... had to have umm... the DVLA had to know about the condition.
14. A1: So that she had to be checked regularly umm... or apply for a new licence at the end of I think every year or something like that [snifles].
15. A1: But umm... one day I...I said to her I don't remember you doing anything about your licence so we found her licence and it was about 4 months out of date [laughs] so so that's it you're not allowed to drive unless you apply for it again. So we applied for it again but I think we used the wrong form.
16. A1: We used the ordinary form and it... it... it... just went on and cos the longer these delays went on, the more she got used to not driving and at that point I was at home cos I hadn't been working... at that point I was home all the time so it weren't so much of a problem you know. But uhh... she did like driving cos that's what she used to do...she's done a few jobs but one of the jobs she kept going back to was parts delivery in the motor trade she used to drive at euro car parts and that sort of thing.
17. A1: Yeah... [goes quiet and swallows]... and she used to do hundreds of miles a day!
18. A1: Just locally yeah, just amazing yeah... but like I...I was talking to some of her colleagues since she retired, she was having a few problems with her memory then. Umm... cos occasionally she'd forget a part, well you know [draws in breath]... umm... so then....even then you know something was going on.
19. A1: She retired at 65 she could have retired at 60 but she wanted to keep going. She retired at 65 but she's 73 and so... so... it's eight years it's been going on really. Uhh...
20. A1: Yeah... uhh... what else? and then umm... as it progressed, we started to... they uhhh... social services I think it was social services got involved [clears throat] more

and umm... it was decided that she should go to [mentions day centre]. You know to give her a bit of...bit of structure to her life I s'pose.

21. A1: Yeah where you met me.
22. A1: And umm... she started off going one day she weren't very keen this time... but once she got to know everybody umm... she quite liked it and we gradually ramped it up till she was on four days a week.
23. A1: Yeah...[looks away]
24. A1: Oh... enormously yeah, yeah. I couldn't have managed without the... er... these people. Yeah
25. A1: Cos the support you get from there is really important you know. Yeah
26. A1: I mean when I first went, when we went up in the carers' group, we all sat around the table and they were all talking about their problems and they... [draws in breath]...then I was aware that they were all looking at me!
27. A1: And I don't do this [Laughs]. So I didn't go for some time after that, but I gradually got back into it. But now I know everybody, you know it's uhh... it's like a chat with your friends really, well they are your friends.

## **Q.2. Perception of being a caregiver**

28. A1: Yeah...
29. A1: Yeah...
30. A1: .... talking with everybody else in the group, people I didn't know, you know
31. A1: Yeah... I'm not the most outgoing person [laughs softly]. So umm... yeah... uhh... emm... what [clears throat] and then it got...cos I've never been able to help her... in the...in er...in the toilet clean her up, and things like that, she's never let me do that so umm....pauses] and then she got so she couldn't manage herself she was having accidents and things like that so then we started having the carers come in...

emmm...[looks down] and then initially they were just coming in twice a day morning and evening, and then problem was on a... ummm... on a Friday when she didn't go to [mentions day centre] and the weekend, I got no support between morning and bedtime

32. A1: You know, so that was getting difficult, so social services put another two visits on soo... for those three days we had four visits a day from social.. from um the carers.... And that was enormous help for me, I mean very often there weren't too much to do to her.

33. A1: They come in to.. you know... really really brightened my life a bit to be honest [laughs]

34. A1: Yeah that's right, well see if ... if she got in a mess... big time she wouldn't let me help her I used to have to phone her daughter, come and help

35. A1: And she lives at [mentions village name] which is I dunno 7 or 8 miles away soo... but then uhh... it all came to head over last Easter. [mentions wife's name] umm... had diarrreah in the middle of the night, bad diarrreah, and umm... she went in the toilet she wouldn't let me help her [pauses] at all [gestures with hands to stress] and she had er...she wore these pull ups you know... and they were all full of... crap you know [laughs] and she was... and I thought I... I can't leave her like that, she was wanting to walk round the house and go back to bed and all the rest of it... soo... umm... I had to call her daughter out in the end but I mean she...she was still [inhales]...I... that's right she came that time and then later in the night this happened about three times in the night I had to keep calling her daughter out... but I mean it got so at one point where I had to... [frowns]... I had to forcibly cut this... pull up and I now know that you can tear em but umm I had to cut this thing off her you know... umm....poor old dog cos he got covered in poo as well you know [A1 & CJ laugh together]... and it all came to a head. So umm... her daughter said I'll phone, you know you need a break cos I was...you

know I'd had enough. So umm... she got involved with social services and it was decided she was gonna have to go for respite. Well I know from talking to other people when they go to respite its nine times out of ten it's a one-way ticket... you know, which is what it proved to be soo... [pauses]. She went over to Risby... she was er...s'posed to be there two weeks but she was there four weeks because I...I wern't happy with it because I was having to pay £335 a week top up.

36. A1: Well, yeah... after a few years I was gonna be skint [laughs]... so I couldn't allow, I can't allow that I can't...I gotta live at the end of all this, you know. Soo... umm... social services er...said well, we'll look to see what hours there is. They came up with two or three, we went and we finished up going to Stowmarket but umm... uhhh... what's it called [mentions care home's name].

37. A1: Which is a Bupa run one, and there's no top up fees there.

38. A1: I mean the only downside there far as I see there's not an en-suite but so what there's a toilet across the road and she's got a umm... a commode, which is more likely used to be honest, and there's not, I don't think there's much in the way of staff there, not so much as there was at [mentions village name]. Other than that I've got no complaints at all. One thing I do like about it I've never known it to smell.

39. A1: The home, cos some places I mean [mentions village name], one day I went in her room and you could cut the air with a knife... it was awful, but I've never known any of that.

40. A1: So you know I'm quite pleased with that.

41. A1: Yeah.. yeah.. yeah.. yeah.

42. A1: So that's umm... but I mean when she was at home very often she wouldn't go to bed. And she'd be up all night..., like I've got to get some sleep, so I made the house safe..., and sometimes I used to pull the the the light switches, pull the fuses out so you couldn't...cos she used to put all the lights on, every single light in the house was

on. But uhh... I got LED lights which made it a bit cheaper, still they're all on, you know. And then sometimes I'd come down in the morning and she's still awake and she you could hear her talking all night long cos you can hear through the floors here. So umm... but the funny thing is when she'd been like that, she was as good as gold the next day....no problem at all... but... then you find the next day she was dead on her feet by tea time you know

43. A1: So she'd go to bed early... and when she went to bed she'd sleep, she was fine.

44. A1: She sleeps all the way through and then when she get up she's really awful [inhales]... couldn't do anything with her [pauses]... but umm...

45. A1: And...and that's still going on in the home. They're having...they're having problems [chuckles] with her the last few days but uhh... The doctor did give her some er... sleeping pills but he said they're addictive so don't give umm... to her unless you absolutely have to so I think there's only about nine in a packet I wasn't giving her any more than about one in a month. You know just when she was really bad... but umm... I think they're giving her more than that where she is now [looks away].

46. A1: Hmm... in fact yesterday they couldn't do anything with her, they managed to get her top on...but they say they couldn't clean her or put...put anything on her bottom half... she wouldn't do anything... wouldn't let um wash, wouldn't let um comb her hair..., swearing at um.... so it s'pposed to be getting emm..I think the doctor's gonna go and have a look at her. She gets, keeps...keeps getting water infection that's another thing and when she's got a water infection that's it you can't do anything with her[inhales]... yeah...

47. A1: Yeah...

48. A1: Yeah...

49. A1: Well...I don't have a problem with it... I mean I've... housework I'm not terribly good at, but [both laugh]. I now know how to use a washing machine
50. A1: And I was.[mentions wife's name] was always a very good cook and that was one of her hobbies.
51. A1: And I wasn't allowed In the kitchen only to wash up ...so but it got to the point where she couldn't manage it anymore, so I took over, so I've been cooking for two or three years now... so you know I cook good plenty enough for me [both laugh]... but when she was here I used to cook proper meals... but since she's been in the home which is like 8 weeks now, sometimes I just have a sandwich I, you know..[A1 inhales]... I can cook if I can be bothered [A1 laughs]. I haven't got any thinner though [both laugh]. I did to start with but then when I was all stressed up over it, it was all horrible... come in the house, an empty house is...is awful you know... it's not nice at all[voice drops and A1 looks away]...yeah. I mean I've been divorced... nearly thirty years ago now... and my wife left... and it's...it's not the same, you know...this is more of a sadness to it now ... whereas, then I was angry really you know... [laughs and inhales sharply]...er...but umm... if I hadn't got me dog I'd be lost...you know...and I got some good friends as well...but it's a big difference... yeah..[long pause]. Some people bottle this stuff up don't they and don't tell anybody and I think that's bad you gotta talk to people, yeah... and you find out who your friends are as well. That's the other thing.
52. A1: Some of them just disappear.
53. A1: Yeah but uhh.[fades off]
54. A1: Yeah yeah yeah yeah.
55. A1: Really yeah yeah yeah, even now I leave the radio on or leaving the tv sometimes... and the lights, so when I come in, it feels like there's somebody here. You know

56. A1: But another thing is see [mentions wife's name] umm... she was always very... house proud if you like [pain in voice detected/feeling of loss undertone?], and she was spick and span... you know... well I've never been quite that bad but you know [laughs], she got so that umm... she used to take things out and fold em put... every drawer and cupboard in this house has got everything in it. You know what I mean [laughs]. You don't know what's in any drawer or you didn't But I'm gradually sorting these out but see that's that... can be pretty gut-wrenching things when you find photographs and thing like that [looks away]
57. A1: Yeah yeah yeah
58. A1: Another problem I had, I dunno why I'm laughing [exhales]..., another problem I had... about two three years ago, I was clearing out cupboard upstairs and I found a box of paperwork... and inside it uhh... was all bank statements and stuff like that. And I found that [mentions wife's name] er.. owed money...
59. A1: And I didn't know anything about this cos we kept our finances separate you know, cos she was working and I was working... umm... but when I got to the bottom of it, she owed a hell of a lot of money.
60. A1: Umm... so I had to get that sorted out as well and I got in touch with an organisation called the C.A.P (Christians Against Poverty)I don't know if you know of it, they've been very helpful but what we've finished up doing was... all her state pension
61. A1: I had to pay towards these debts.
62. A1: And she's been paying them off over two years now..., but she's paid half of it but there's like, you know... 28 thousand quid.
63. A1: That's how much she owed... so there's about half of that left now...
64. A1: ...so they trying to get it written off I dunno whether they are having much success with that but we'll see what happens... yeah. So that was a hell of a shock that was.

Cos I knew nothing about it... and she...don't know, she don't know anything about it either now. Cos... what she was doing was getting the correspondence and anything that came in to do with her she was just tearing it up. So although she didn't, I dunno how much she owed to start with but it certainly wasn't that much that's just been adding...

65. A1: ... interest on...selling the debts on and the rest of it.

66. A1: soo...umm... that was a right real real shock that was, in fact if she hadn't have had dementia [inhales] it would probably have finished us... finish us as a couple I reckon. You know, she'd have been down the road. So that left a nasty taste in my mouth you know.

67. A1: So yeah it's not been easy! [Laughs]

68. A1: ...this is all credit cards

69. A1: And store cards, nothing... I can say nothing serious you know what I mean, secondary debt is what they call it [Clears throat loudly]

70. A1: Yeah.

71. A1: Uhhh... I 'spose when I retired [laughs]

72. CJ: Right

73. A1: So I've been retired umm... four years I think it is this year ... or is it five, I can't remember now... but yeah cos I did, I retired when I was 67 I did an extra couple of years.

74. A1: [pauses] but family kept saying you really ought to be here, you know mum needs you here, so I thought right [inhales]. Then the chance for voluntary redundancy came up so I said yes, I'm having it [laughs]... that was quite fortuitous. Yeah...

75. A1: I don't know I mean you think you retire and you think we'll be able to [inhales sharply]... you now plenty of money and you'll go on holidays and all the rest of it... and none of that happened I mean I haven't had a holiday since I retired. So uhh... I

don't think at any point I suddenly realised I was a carer it's just something that grows on ya you know. When you have to start filling in forms saying you're a carer you know [laughs]...that sort of thing

76. A1: When you gotta apply for... I forgotten what it's called now [long pause]... the carers benefit. What's it called, I can't think of it now. I dunno.
77. A1: Attendants allowance... and they came and helped me fill the forms in actually, see this is another thing all these different agencies, I was very confused as to who was who, you know I mean you got NHS, you got umm... umm... what's it called... Alzheimer's society all those, they all seem to talk to each other and share these different roles.
78. A1: Social services, to me, I weren't hundred percent sure who they are or how they all integrated.
79. A1: You know how I mean well I think there I don't know. I was a bit confused to start with about how who to turn to for various things. You know but they seem to sort itself out in the end.
80. A1: Yeah well there wont a process it just sort of happened.
81. A1: Yeah.
82. A1: Yeah well I purposely didn't dig into what was gonna happen cos I didn't really wanna go there if I'm honest [laughs] especially dealing with care home stuff like that you know. I been doing a bit of reading up on that finding out what you could/couldn't do. How much money you were allowed what's it gonna cost ya. Like it's stressful enough without having to deal with all that.
83. A1: Oh I was really stressed yeah yeah yeah [fades] You get to the point were you just put your loved one away as it were then suddenly you gotta start figuring out how you gotta pay for it all. You know cos if you got more than 24,250 I think it is in the bank you don't get any help at all.

84. A1: So I had to make sure that [mentions wife's name] didn't have that well she hasn't cos she's paying her debts so. [Laughs] If she hadn't been if she'd had that much money then you know don't get any help whatsoever, you're on your own.
85. A1: Oh yeah yeah yeah. [Very quietly] yeah if you're having to pay a thousand pound a week that's stressful to anybody.

### **Q.3. Account of caregiving challenges**

86. A1: Just dealing with her on a day to day basis you know how she was. Umm she could be quite verbally aggressive not physically.
87. A1: Running me down all the time.
88. A1: Your useless you don't do anything! You don't do this you don't do that you know. Oh some of umm I didn't you know yeah.
89. A1: Well it makes you feel pretty low obviously you know, but after a while you get to realise that this is just a condition that she's got and you tend to, it goes over your head a bit but you know it's still there. It doesn't have no effect if you see what I mean.
90. A1: Yeah
91. A1: How did I deal with it? I used to go out and get in my Morgan sports car and go for a thrash!
92. A1: When I came back I felt a lot better.
93. A1: [Laughing] Yeah you gotta have something to you know something to look forward to and.
94. A1: And I brought that two years before I retired and that's something I've always wanted!
95. A1: I gotta I've got a workshop I mean it's not very big but I've got uhh I used to be a design engineer.

96. A1: But I finished up as a design engineer, most of my working life I was actually manufacturing. Which is Engineering, soo... I say two thirds of my working life I was making parts that other people designed I like making stuff and then the last third I was designing stuff for other people to make so I never saw that. [they laugh] So now I can I've got a laid and a millin machine out there so I've got I can keep my skills.
97. A1: Going you know what I mean
98. A1: and I can make what I want. So there that's what I do.
99. A1: Yeah I can make parts for my friends got classic cars and stuff like that. I make....  
All sorts of bits and pieces.
100. A1: Well it makes you feel better about yourself don't ya cos otherwise I've spent what I left school at 15 finished at 67 all that experience when you retire for a lot of people it's gone. It's a waste!
101. A1: You know what I mean, I mean the last ten years I was using umm I was using a cat system to design things in 3D.
102. A1: And uhh which I quite enjoyed like I say that's all gone now. Well it's not all gone it's still there but it's getting rusty cos I can't afford the software to to to do that anymore.
103. A1: That's industrial stuff, thousands of pounds a seat you know.
104. A1: No
105. A1: Its interesting really interesting stuff that it really is. See if it hadn't have been for [mentions wife's name] I would have gone and got a different job when I retired.
106. A1: Yeah yeah
107. A1: No no it wasn't a plan you know just none of this was planned really other than working extra years to get my pension up a bit.
108. A1: Yeah you know I don't need financially I don't need to work but I like keeping busy.

109. A1: [Laughs] Well I might have a glass of whisky occasionally! [both laugh] Yeah but umm ohh I'd say having the careers in you know apart from the care aspect that they did for [mentions wife's name]. It was nice having somebody in to talk to you know. Uhh I really missed them when she went in the home yeah but uhh yeah
110. A1: one of them phoned me back to find out how [mentions wife's name] was and I was really touched by that yeah but other than that they just disappeared don't they [laughs] yeah [coughs].
111. A1: Yeah yeah I'm fine.

#### **Q.4. Account of caregiving expectations**

112. A1: No I don't think so no because I say you are expecting because it happened so slowly you know. But I didn't from but I didn't at day one go and say to myself I wanna know what how this disease can progress what problems I'm gonna have. I can have let them happen when I happen you know got enough to worry about without doing that perhaps it's a bit of a head in the sand view but there you go that's me.
113. A1: Well I did yeah [laughs]
114. A1: No I would have felt worse yeah. I did what was right for me yeah.
115. A1: She could be a bit difficult and then another day she's really nice you know so yeah. I mean she used to take the dog for a walk 3 times a day.
116. A1: And that dropped off you know I got so I didn't like Letting her out on her own she used to go up town every day you know when she retired just get on the bus and go up it's only about 4 miles.
117. A1: And go do a bit shopping and then come back because that's what she's used to doing she used to go out to work every day you no she didn't wanna be stuck in the house.

118. A1: Yeah yeah yeah. I mean anything I used to notice when she'd go come home she would always have a pocket or a purse bulging with change and then I realised what it was. She couldn't work out the change on the money.
119. A1: so she used to give a note for everything buy everything with she'd pay with a note.
120. A1: So she's have all this change building up [laughs]
121. A1: Couple of times she went on a walkabout, one time I got she was downstairs, and I was having a shower I said I'm just gonna have a shower and when I got out she'd gone so I thought
122. A1: Yes she gone out the house so I wandered round couldn't find so I thought I'd better get me bike out got that out the garage and cycled around the villages I was just get my bike out and there Land Rover pulled up [mentions wife's name] got out the passenger door
123. A1: And off it went and I later found out that [mentions wife's name] was the other side of the about mile or so off the road and in the sticks and like and this lady who luckily knew who she was umm picked her up and brought her back home again and then later and I spoke to this lady later an [mentions wife's name] was saying to her do ya know my husband's got dementia you know laughs so and that was that was the time when she cos she wouldn't except that she's got dementia.
124. A1: So for a long long time we didn't even dare mention it you know, but that that was interesting you know that point she said I got dementia laughs perhaps I have oh dear.
125. A1: Yeah yeah yeah
126. AT I thought it was funny!
127. A1: Yeah yeah
128. A1: She went missing uptown as well

129. She went missing uptown once I when she was a [mentions day centre] I took her to the dentist in the town.
130. A1: I don't if you know Bury do you?
131. A1: Well with parked at [mentions location name].
132. A1: Well the dentist is over the road.
133. A1: So I said stay in the car I will just go and pay you know for the car park so I went which is just around the corner 50 feet away probably. Went around the corner put the money in you know when I came back [mentions wife's name] had gone. I couldn't I walked around the car park couldn't see her anywhere, I thought well maybe she's gone into the dentist because she must know where it was and they hadn't seen now I walked round Waitrose and they hadn't seen her she wasn't in Halfords so I thought I'd better do something about this so I phoned the police and ummm they they put out a description to the PCSO I think. They asked me to wait outside of Halfords which I did and about half an hour later police car pulled in just as they pulled in I spotted her about 50 yards away, she was walking along looking a bit confused you know. So I went and grabbed but you know I didn't know where she'd been but uhhh had to you know keep an eye on her after that yeah.
134. A1: I mean I thought someone will find her you know [laughs]
135. A1: I mean I was worried that not that overly worried I mean her daughter was very worried.
136. A1: I mean she can't be that far away.

**Q.5. Account of choice making**

137. A1: Now know if there is a problem I'd do something about it. I got so I would lock the gates so she could get in the garden but not outside.

138. But umm I was told I shouldn't lock her in because I was infringing her what was it human rights or whatever it was!
139. A1: She got a right go at getting run over their she, it was ridiculous gotta be sensible don't ya you know and the gas cooker couldn't I couldn't switch the gas off cos its gas central heating so I I drilled all the gas knobs
140. A1: On the front an made a rod with a little locking collar on the end that you use with a little Allen key so that that was that made that safe
141. A1: So the electric lights pulled some of the fuses out left some of them obviously but um she'd use and sugar anything sweet she would sit in the jar of jam so that was that towards the end that was starting to cause a little bit of a problem.
142. A1: Yeah yeah she was a really sweet tooth so I mean that was the same point as she needed the care home so that didn't that wasn't a problem any more so yeah.
143. A1: Bit of a rollercoaster really I mean we're not there yet but.
144. A1: Yeah!

#### **Q.6. Account of the effect of caregiving**

145. A1: But I do feel more distance between us you know because I'm not with her all the time now you know I'm getting some of my life back but umm it does make you feel you know
146. A1: Yeah I dunno mixed feelings really uhh umm I can't get on with my life cos I'm still married [laughs] Do you know what I mean. Not that I particularly want to at the moment but there you go!
147. A1: Life's like that in my experience jogging along and every now and then you get a kick in the nuts that's what this was yeah!
148. A1: I'm it's made me more tolerant.

149. A1: Cos initially I wouldn't do with it you know I used to get angry you know. One time she she got up in the middle of the night because we never used to have the lights on she got up in the middle of the night I could hear her rummaging about what was she doing so I put the light on and we got a waste paper basket in the corner of the bedroom.
150. A1: And she was weeing in it, she's sitting on it cos she thought it was the toilet.
151. A1: She did that once on the way to the toilet.
152. Another time she did it sitting on a chair in the bedroom.
153. A1: That really freaked me out cos I didn't like that at all.
154. A1: But then you get over it I figured out you know she's getting confused as to where she is thas so what I learned is I left the bathroom light on and the door cracked open cos it's only next to the bedroom.
155. A1: And umm an bought one of these little lights that you plug-in you know.
156. A1: A nightlight left that on didn't have any problems like that anymore because she knew where she was going you know soo.
157. A1: I like to think I'm tolerant [laughs] maybe I haven't (laughs). You have to see the funny side of it as well that the other thing is not all it's not all miserable you know.
158. A1: There are funny sides about it but uhh yeah.
159. A1: And the neighbours have been good that's a thing got a couple of neighbours and they umm cos they've seen the progression as well.
160. A1: But they they were quite tolerant even though [mentions wife's name] used to be quite abusive to some of them
161. A1: The lady that used to live just up there [mentions wife's name] would tell her to F off and all the rest of of you know.
162. A1: Yeah but towards the end towards the latter part the lady over there who she quite liked she turned on [laughs]

163. A1: Yeah they still carried on coming cos they realised you know.
164. A1: next time she'll see as she throw her arms around her you know is just how things are you know yeah.
165. AT Yeah the lady over the roads her husband died two Christmases ago.
166. A1: And she gets very lonely so she used to phone [mentions wife's name] up every other day and now she phones me [laughs].
167. A1: I don't mind I don't.
168. A1: No...that's pretty rotten being on your own that's why they're like that both of them live on their own.
169. A1: Yeah I think so yeah.
170. A1: Yeah exactly.
171. A1: That's it yeah.
172. A1: I mean the one that's got dementia or I think she do she will come up to me I mean I tolerate her whereas other neighbours they don't they get annoyed with her you know I mean.
173. A1: But are she'll come in and she'll... sometimes I get a bit of shopping for her, I'll take it round and I'll say here's your shopping she says right how much is that £2.50 or whatever it was and she give me the £2.50 and I'll say right better go get my tea or whatever it is and she'll say right do I owe you any money I say no you've paid me. I mean I'll sit at home and they'll be a tap on the door "I think I might owe you some money." No you don't you've paid me you know [laughs]. So there you go.
174. A1: she's on her own but she's been on her own all along bless her and she's going blind now as well that doesn't help so there's always someone in a worse.. worse off position than yourself if you look around yeah.
175. A1: Yeah I think so but it's just reinforced it really!
176. A1: Hmm

177. A1: Convert me??
178. A1: Does that old does that comfort me, probably a little bit yeah but there you go.
179. A1: One thing I just thought of when I first, when [mentions wife's name] was first umm diagnosed umm I went on a carers course six or twelve weeks or something over at Needham market umm.
180. A1: Umm I forget I forget how I got involved in it now it could have been yeah it wasn't the council it was I think Suffolk family carers.
181. AJ. But at that point anybody talking about their problems about their partners or the people they cared for and [mentions wife's name] was still driving she hadn't got we wern't far enough down the road you know I mean so I felt a bit of a fraud being there you know I mean?
182. A1: So, I don't think it did me any good really going there.

#### **Q.7. Account of what has been helpful**

183. A1: Cos all I came away was knowing what the problems could be yeah.
184. A1: Yeah yeah it was actually.
185. A1: I don't know if that helped at all to be honest, it was too early on really yeah I as far as I was concerned at that point I wasn't a carer cos I was at work then as I say [mentions wife's name] was still driving so it was really early on you know but anyway yeah..
186. A1: Yeah I mean
187. A1: I do know I think you more tolerant of of the person you love aren't you or you should be yeah I don't know.

#### **Q.8. Account of future plans**

188. A1: I don't think I don't think so I mean she tried all these various medications I think there are four aren't there and I mean she tried those.

189. A1: And all of them upset her.
190. A1: Well well well she said they did maybe they didn't you know I don't know [laughs]  
no I think
191. A1: I don't think I would have done anything differently no uhhh perhaps kept my  
temper a bit a bit early on yeah. But again [mentions day centre] have been really  
good in that respect you know.
192. A1: Yeah even now yeah.
193. A1: That's right this still being helpful. Yeah
194. A1: Well I mean there are people that carers that go there the carers group who are  
further advanced than me if you like put it that way you know umm there's one chap  
there his wife died you know he still comes see that's good to talk to him because you  
know he's had problems that I haven't seen yet you know.
195. A1: Yeah so umm
196. A1: Yeah yeah yeah and it's just a matter to get out and to meet people that's good in  
itself. [clears throat] yeah.
197. A1: You haven't been here that long have ya.
198. Is there anything else you'd like to tell me all in all is there anything else maybe  
what's the what's the care like now uhh what are your thoughts now is no longer in  
the house.
199. A1: Well I don't think she's getting the care isn't as it was when she was at home.  
She was clean tidy and properly dressed but now you know she'll be sitting about  
with no knickers on for a while because she won't let them help her and things like  
that in her room you know.
200. A1: But then you know she's getting worse she's gonna get worse.
201. A1: [pauses] Well I don't know cos she probably wouldn't have let me do it either so  
you know [laughs] it's the best of a bad job really but uhhh yeah. But she she. I mean

she's quite apt she'll take her knickers off in the common room there you know things like that you know there's no she doesn't know what she's doing you know it doesn't upset her cos its not the same person really. You know but uhh that's it because the person you know has gone really she's not the [mentions wife's name] I knew years ago you know not at all that's you know. I've got some photographs show you a few photos.

202. A1: I've got hundreds of photographs on my computer that's one of the day she came home for when she finished work her last day at work.

203. A1: so that would have been when she very first had slight problems.

204. A1: Got all sorts in here let me see for a later one. I haven't got a later one. Now this is that's her friend.

205. A1: I know she's been a really good friend she goes and sees every day.. not every day every week.

206. A1: That's about 10 years ago as well. I I haven't got any I should have got some to compare with really.

207. A1: and that was our six years birthday that was in Rick Stines restaurant in Padstow do know it.

208. A1: He's a celebrity chef ain't he.

209. A1: Well that's uhh 14 years ago.

210. A1: But I mean you've never met have you?

211. A1: she weighs about seven stone now she was fairly well-padded at one point.

212. A1: That's a nice one I like that one.

213. A1: Yeah I haven't got got any really nice pictures of her but there on there somewhere. Where's the other one? [shuffles about while tutting for a while]. This is a she was sitting there she had an ice cream.

214. A1: That's still loading

215. A1: I suppose that's taken out from the cloud innit.
216. A1: Never known it do that before [laughs] Ohh
217. A1: I reckon this is getting full up.
218. A1: Yeah
219. A1: Yeah I mean you see she's not what she was there really.
220. A1: That's my granddaughters
221. A1: Look ones five and one's three that couple of weeks ago I had them to myself all day long I took out for the day it was a bit daunting that my daughter couldn't find anyone to look after them I thought I'd give it a go and I thought as I done the right thing here and I had a lovely day with them.
222. A1: That's [mentions wife's name] sitting on the sofa [laughs]
223. A1: An that one That's my nosy neighbour.
224. A1: Where's the other one I had on of her looking through the garage door somewhere. I dunno where that is. That one [laughs] very nice that! Oh go away [to computer] there it is that's a nice one I thought.
225. A1: See that was
226. A1: See that was August 15 so that was two years no three years ago now innit.  
Yeah there you go.
227. A1: Have you got your coffee
228. A1: Do you want me to stick it in the microwave or make you another one?
229. A1: you sure you sure?
230. A1: Its all right

[Recording ends]

## Appendix 9: Ethics - approval letter, sponsorship and amendments



### West Midlands - Coventry & Warwickshire Research Ethics Committee

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

22 November 2018

Charles James  
Faculty of Health and Medicine  
Furness College  
Bailrigg, Lancaster  
LA1 4YG

Dear Charles James

<b>Study title:</b>	<b>Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.</b>
<b>REC reference:</b>	<b>18/WM/0001</b>
<b>Amendment number:</b>	<b>SREC004</b>
<b>Amendment date:</b>	<b>25 October 2018</b>
<b>IRAS project ID:</b>	<b>231253</b>

The above amendment was reviewed by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The subcommittee agreed the amendment did not present any ethical issues.

### Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Amendment Cover Letter - ACL004.pdf]	CL004	25 October 2018
Letters of invitation to participant [Email-Contact-(Using-JDR-Tool)---EC004.pdf]	MDIG004	25 October 2018
Notice of Substantial Amendment (non-CTIMP)	SREC004	25 October 2018
Other [JDR Guide (JG004).pdf]	JG004	25 October 2018
Participant information sheet (PIS) [JDR-Participant-Information-Sheet (JPIS004).pdf]	JPIS004	25 October 2018

Research protocol or project proposal [Moral Distress in Moderate to Advanced Dementia Care - MDIG004.pdf]	MDIG004	25 October 2018
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### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

### **Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>18/WM/0001:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely



**Dr Helen Brittain**  
**Chair**

E-mail: [NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net](mailto:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*



# Health Research Authority

**West Midlands - Coventry & Warwickshire Research Ethics Committee**

**Attendance at Sub-Committee of the REC meeting on 22 November 2018**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Helen Brittain	Clinical Psychologist Retired	Yes	
Dr Ronald Jubb	Retired Consultant Rheumatologist	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Adam Garretty	REC Assistant



# Health Research Authority

## West Midlands - Coventry & Warwickshire Research Ethics Committee

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

18 July 2018

Charles James  
Faculty of Health and Medicine  
Furness College  
Bailrigg, Lancaster  
LA1 4YG

Dear Charles James

<b>Study title:</b>	<b>Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.</b>
<b>REC reference:</b>	<b>18/WM/0001</b>
<b>Protocol number:</b>	<b>TBC</b>
<b>Amendment number:</b>	<b>MDIG003</b>
<b>Amendment date:</b>	<b>10 June 2018</b>
<b>IRAS project ID:</b>	<b>231253</b>

The above amendment was reviewed by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The sub-committee agreed the amendment did not present any ethical issues.

### Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Research Recruitment Flyer - RRF001.pdf]	RRF001	10 June 2018
Covering letter on headed paper [Amendment Cover Letter - ACL001.pdf]		10 June 2018
Notice of Substantial Amendment (non-CTIMP)	MDIG003	10 June 2018
Other [Reply Slip - RS003.pdf]	RS003	10 June 2018
Research protocol or project proposal [Moral Distress in Moderate to Advanced Dementia Care -MDIG003.pdf]	MDIG003	10 June 2018

### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

### **Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>18/WM/0001:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



**Dr Ronald Jubb**  
Chair

E-mail: [NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net](mailto:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*



# Health Research Authority

## West Midlands - Coventry & Warwickshire Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 05 July 2018

### Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>
Dr Josephine Ashcroft	Retired Research Nurse	Yes
Dr Ronald Jubb (Chair)	Retired Consultant Rheumatologist	Yes

### Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Adam Garretty	REC Assistant



**Health Research Authority**

**West Midlands - Coventry & Warwickshire Research Ethics Committee**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

**Please note:** This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

14 March 2018

Professor Catherine Walshe  
C52, Furness Building,  
Lancaster University  
Bailrigg, Lancaster,  
LA1 4YG

Dear Professor Walshe

**Study title:** Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.  
**REC reference:** 18/WM/0001  
**Protocol number:** TBC  
**IRAS project ID:** 231253

Thank you for your letter of 02/03/2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net) outlining the reasons for your request.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

## **Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

## **Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

## **Ethical review of research sites**

## NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## Non-NHS sites

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Amendments Cover Letter]	CL001	26 February 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		16 November 2017
Interview schedules or topic guides for participants	TG001	13 November 2017
Letter from sponsor		16 November 2017
Letters of invitation to participant	PI002	26 February 2018
Other	TCA001	13 November 2017
Other	RAM001	13 November 2017
Other		13 November 2017
Other	SI001	13 November 2017
Other [SOE]		13 November 2017
Other [SOA]		13 November 2017
Other	ST001	13 November 2017
Other [Study Supervisors' CVs]		14 November 2017
Other		
Other	TA001	26 February 2018
Other	MDIG002	26 February 2018
Other [Charles James' CV]	CV002	21 February 2018
Other	LWP001	26 February 2018
Other	LWCS001	26 February 2018
Other	DIP001	26 February 2018
Other	RS002	26 February 2018
Other [Reply Slip]	RS001	13 November 2017
Participant consent form	CF002	26 February 2018
Participant information sheet (PIS)	PIS002	26 February 2018
REC Application Form [SC_Form_07122017]		07 December 2017
Research protocol or project proposal	MDIG001	13 November 2017
Summary CV for Chief Investigator (CI) [CV]		13 November 2017

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research

Ethics Committees in the UK.

### **After ethical review**

#### Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

**18/WM/0001**

**Please quote this number on all correspondence**

With the Committee’s best wishes for the success of this project.

Yours sincerely



**Dr Helen Brittain**  
**Chair**

Email: [NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net](mailto:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net)

*Enclosures:* “After ethical review – guidance for researchers” [\[SL-AR2\]](#)

**West Midlands - Coventry & Warwickshire Research Ethics Committee**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

16 November 2018

Charles James  
Faculty of Health and Medicine  
Furness College  
Bailrigg, Lancaster  
LA1 4YG

Dear Charles James

<b>Study title:</b>	<b>Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.</b>
<b>REC reference:</b>	<b>18/WM/0001</b>
<b>Protocol number:</b>	<b>TBC</b>
<b>Amendment number:</b>	<b>SREC004</b>
<b>Amendment date:</b>	<b>25 October 2018</b>
<b>IRAS project ID:</b>	<b>231253</b>

Thank you for submitting the above amendment, which was received on 09 November 2018. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

**Documents received**

The documents to be reviewed are as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Amendment Cover Letter - ACL004.pdf]	CL004	25 October 2018
Letters of invitation to participant [Email-Contact-(Using-JDR-Tool)---EC004.pdf]	MDIG004	25 October 2018
Notice of Substantial Amendment (non-CTIMP)	SREC004	25 October 2018
Other [JDR Guide (JG004).pdf]	JG004	25 October 2018
Participant information sheet (PIS) [JDR-Participant-Information-Sheet (JPIS004).pdf]	JPIS004	25 October 2018
Research protocol or project proposal [Moral Distress in Moderate to Advanced Dementia Care - MDIG004.pdf]	MDIG004	25 October 2018

**Notification of the Committee's decision**



## Health Research Authority

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

### **R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our Research Ethics Service Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

**18/WM/0001:**

**Please quote this number on all correspondence**

Yours sincerely

**Adam Garretty**  
**REC Assistant**

Email: [NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net](mailto:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net)

Copy to: *Mr Charles James*

**West Midlands - Coventry & Warwickshire Research Ethics Committee**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

05 July 2018

Charles James  
Faculty of Health and Medicine  
Furness College  
Bailrigg, Lancaster  
LA1 4YG

Dear Charles James

<b>Study title:</b>	<b>Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers' Experience of Home-Based Care Provision towards the End of Life.</b>
<b>REC reference:</b>	<b>18/WM/0001</b>
<b>Amendment number:</b>	<b>MDIG003</b>
<b>Amendment date:</b>	<b>10 June 2018</b>
<b>IRAS project ID:</b>	<b>231253</b>

Thank you for submitting the above amendment, which was received on 21 June 2018. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Sub-Committee of the REC at its next meeting.

**Documents received**

The documents to be reviewed are as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Research Recruitment Flyer - RRF001.pdf]	RRF001	10 June 2018
Covering letter on headed paper [Amendment Cover Letter - ACL001.pdf]		10 June 2018
Notice of Substantial Amendment (non-CTIMP)	MDIG003	10 June 2018
Other [Reply Slip - RS003.pdf]	RS003	10 June 2018
Research protocol or project proposal [Moral Distress in Moderate to Advanced Dementia Care -MDIG003.pdf]	MDIG003	10 June 2018

**Notification of the Committee's decision**

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

**R&D approval**

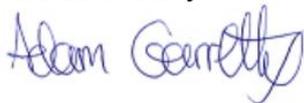
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our Research Ethics Service Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

**18/WM/0001:**

**Please quote this number on all correspondence**

Yours sincerely



**Adam Garretty**  
**REC Assistant**

Email: [NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net](mailto:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net)

Copy to:

*Mr Charles James*

Applicant name: Charles James  
Supervisors: Catherine Walsh and Katherine Froggatt  
Department: Health Research

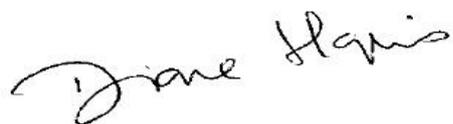
16 November 2017

Dear Charles

**Re: An exploration of the informal caregivers' experience of care provision for people with a moderate to advanced dementia who live at home**

The University of Lancaster undertakes to perform the role of sponsor in the matter of the work described in the accompanying grant application. As sponsor we assume responsibility for monitoring and enforcement of research governance. As principal investigator you will confirm that the institution's obligations are met by ensuring that, before the research commences and during the full term of the grant, all the necessary legal and regulatory requirements are met in order to conduct the research, and all the necessary licenses and approvals have been obtained. The Institution has in place formal procedures for managing the process for obtaining any necessary or appropriate ethical approval for this grant. Full ethical approval must be in place before the research commences and should be reviewed at all relevant times during the grant.

Yours sincerely,



*PP* Professor Roger Pickup  
Associate Dean for Research  
Chair Faculty of Health and Medicine Research Ethics Committee.

## Appendix 10: Distress protocol

Indication of Distress	Signs	Engage	Action	Review
Stage 1 (Mild)	Verbal indication of feeling of distress, tearfulness, sobbing, difficulty in speaking, distraction or restlessness	<p>(a) Pause the interview</p> <p>(b) Ask the participant how they are feeling</p> <p>(c) Ask - shall we stop for a break?</p> <p>(d) Ask – would you like to continue</p> <p>(e) Make participant aware that it is possible to discontinue the interview if they wish</p>	<p><b>Question:</b> Ask the participant if they wish to continue.</p> <p>If ‘Yes’ – resume the interview</p> <p>If ‘No’ – follow steps in Stage 2 below</p>	Follow up participant with a courtesy call within 24 hours
Stage 2 (Severe)	Sudden incoherence, panic attack, shaking, uncontrolled crying, intrusive flashbacks	Terminate the interview immediately	Terminate the interview immediately, engage the participant in breathing exercise in cases of panic attack, with participant’s consent, call their GP. Suggest counselling services with details on the information sheet	Follow up participant with a courtesy call within 24 hours. Consent may be necessary
Stage 3 (Extreme)	Physical agitation, aggression, psychosis	Terminate the interview immediately	With participant’s consent, call their GP immediately. Suggest counselling services with details on the information sheet	Follow up participant with a courtesy call within 24 hours. Consent may be necessary

## Appendix 11: Disclosure protocol

No	Type of Disclosure	Determining Criteria	Action	Guidance
1	<ul style="list-style-type: none"> <li>Participant's disclosure signifies a risk of harm to the person receiving care, researcher or the participant themselves</li> </ul>	<ul style="list-style-type: none"> <li>Participant is likely to be harmed by breach of confidentiality: Y <input type="checkbox"/> N <input type="checkbox"/></li> <li>Is this likely to be a 'cry for help'? Y <input type="checkbox"/> N <input type="checkbox"/></li> <li>Is a criminal offence likely? Y <input type="checkbox"/> N <input type="checkbox"/></li> </ul>	<ul style="list-style-type: none"> <li>Report to study supervisor? <input type="checkbox"/></li> <li>Report to the police? <input type="checkbox"/></li> <li>Report to care provider? <input type="checkbox"/></li> <li>Report to other? <input type="checkbox"/></li> </ul> <p>Comment: _____</p>	<ul style="list-style-type: none"> <li>Disclosure of confidential information will be limited to people who have the right to know e.g. study supervisor, the police</li> <li>In breaching confidentiality, the researcher would ensure that consent form given to participants before taking part in the study clearly outlines the potential consequences of disclosures which highlight a risk of abuse or harm especially to the person receiving care</li> <li>In breaching confidentiality following a disclosure, the researcher would ensure that the damage of the disclosure to the participant is limited and breach of privacy will be minimised to include only the necessary information to reduce the risk of abuse or harm.</li> </ul>
2	<ul style="list-style-type: none"> <li>Participant's disclosure signifies past harm or abuse to the person receiving care or to self</li> </ul>	<ul style="list-style-type: none"> <li>Participant is likely to be harmed by breach of privacy: Y <input type="checkbox"/> N <input type="checkbox"/></li> <li>Is this likely to be a 'cry for help'? Y <input type="checkbox"/> N <input type="checkbox"/></li> <li>Is a criminal offence likely? Y <input type="checkbox"/> N <input type="checkbox"/></li> </ul>	<ul style="list-style-type: none"> <li>Report to study supervisor? <input type="checkbox"/></li> <li>Report to the police? <input type="checkbox"/></li> <li>Report to care provider? <input type="checkbox"/></li> <li>Report to other? <input type="checkbox"/></li> </ul> <p>Comment: _____</p>	
3	<ul style="list-style-type: none"> <li>Participant's disclosure signifies poor care provision for person receiving care.</li> </ul>	<ul style="list-style-type: none"> <li>Participant is likely to be harmed by breach of privacy: Y <input type="checkbox"/> N <input type="checkbox"/></li> <li>Is this likely to be a 'cry for help'? Y <input type="checkbox"/> N <input type="checkbox"/></li> <li>Is a criminal offence likely? Y <input type="checkbox"/> N <input type="checkbox"/></li> </ul>	<ul style="list-style-type: none"> <li>Report to study supervisor? <input type="checkbox"/></li> <li>Report to the police? <input type="checkbox"/></li> <li>Report to care provider? <input type="checkbox"/></li> <li>Report to other? <input type="checkbox"/></li> </ul> <p>Comment: _____</p>	

## Appendix 12: Risk assessment and management

Identified Risks	Likelihood	Potential Impact/Outcome	Possible Risk Management/Mitigating Factors
Identify the risks/hazards present	High/Medium /Low	Who might be harmed and how?	Evaluate the risks and decide on possible precautions, e.g., Health & Safety
Travel risks to location of research project: <ul style="list-style-type: none"> <li>Road/rail accident</li> <li>Physical assault</li> </ul>	Low	Researcher: <ul style="list-style-type: none"> <li>Physical injury</li> <li>Psychological harm</li> </ul>	<ul style="list-style-type: none"> <li>Travel with companion</li> <li>Awareness of options for mode of travel</li> <li>Awareness of physical environment, e.g., alleyways, open spaces</li> <li>Researcher to be aware of health and safety at interview location e.g.: <ul style="list-style-type: none"> <li>Location of fire alarms (if any) &amp; exits</li> <li>Researcher to carry a panic alarm</li> </ul> </li> </ul>
Discussion of a sensitive topic in the interview has potential to cause distress to participant	Medium	Participant: <ul style="list-style-type: none"> <li>Psychological stress</li> </ul> Researcher: <ul style="list-style-type: none"> <li>Anxiety about dealing with this complex situation</li> </ul>	<ul style="list-style-type: none"> <li>Offer to cease interview</li> <li>Follow guidance from Draucker et al (2009) protocol. (Appendix 7)</li> <li>Signpost participant to external/internal support services</li> </ul>
Whistleblowing	Low	Participant: <ul style="list-style-type: none"> <li>Emotional distress from disclosing the event</li> <li>Bias/prejudice/anger as a result of disclosure</li> </ul>	<ul style="list-style-type: none"> <li>Inform participant of limits to confidentiality in Participant Information Sheet (PIS)</li> <li>At time of disclosure, cease interview</li> <li>Pass on details of the event to the supervisors</li> <li>Follow the Care Quality Commission (CQC) protocol for poor practice</li> </ul>
Data collection with groups of participants e.g. spouse and children of the person receiving care	Low	Disagreements or conflicts between people	<ul style="list-style-type: none"> <li>Confirm researcher's experience and skill in group facilitation</li> <li>Offer to reschedule the interview</li> </ul>

Data collection taking place in an unfamiliar location with people not known to or previously spoken to by the researcher e.g. children or other family of the person receiving care	High	Researcher: physical injury or psychological harm	<ul style="list-style-type: none"> <li>• Visit location prior to data collection to assess possible risks associated with the environment. If it is the domestic home of the participant, assess the external environment and have a backup person to travel with</li> <li>• Use this information to plan the session</li> <li>• Allow extra time to familiarise participants with research</li> <li>• Researcher to have contact details and means of making timely contact with back up person</li> <li>• Offer to reschedule the interview</li> </ul>
Disclosure of information about poor practice	Low	Immediate, urgent or prompt response may be required from service providers	<ul style="list-style-type: none"> <li>• Ensure that participant is informed at the beginning of the interview that confidentiality may have to be broken in cases of disclosures.</li> <li>• Inform participant that the CQC protocol for reporting concerns will be followed.</li> </ul>
Disclosure of unmet health or social care needs	Medium	Immediate, urgent or prompt response may be required from service providers	<ul style="list-style-type: none"> <li>• Ensure that participant is informed at the beginning of the interview that confidentiality may have to be broken in cases of disclosures.</li> <li>• Inform participant that the CQC protocol for reporting concerns will be followed for safety purposes.</li> </ul>
Research participant in danger of harm to self or others	Low	Immediate or urgent response may be required from service providers or emergency services	<ul style="list-style-type: none"> <li>• Ensure that participant is informed at the beginning of the interview that confidentiality may have to be broken in cases of disclosures.</li> <li>• Inform participant that the CQC protocol for reporting concerns will be followed for crime prevention.</li> </ul>

## Appendix 13: Lone working protocol

Step	Safety Precaution for Visit	Managing Aggression during Lone Working	Action following an Incident	Communication Procedure
1	<p>Obtain all available information about participant and family from Care Coordinator</p> <p>Discuss the appropriateness of location choice with research supervisors prior to the interview.</p>	<p><b>Stage 1</b></p> <p>Stay calm, speak gently and slowly</p> <p>Do not get into an argument</p> <p>Be aware of the environment and signs of potential aggression.</p>	<p><b>Stage 1</b></p> <p>Take a deep breath and allow time to recover once safely removed from all harm</p>	<p><b>Stage 1</b></p> <p>Researcher to decide and arrange nominated person 1 week prior to each interview. This may be either the study supervisors (available Mon-Fri 9am-5pm), or the on-call manager at the researcher's local workplace, Avican Support Ltd (available Mon-Sun 5pm -8am).</p> <p>Researcher leaves contact sheet in secure Lancaster Box for supervisors at least 48 hours before each interview. A copy is also supplied to the nominated person</p> <p>Researcher contacts nominated person once outside the interview location</p>
2	<p>Dress appropriately</p> <p>Be courteous and respect people's culture, religion and other differences</p> <p>Inform family of whereabouts and estimated time of departure from lone working location</p>	<p><b>Stage 2</b></p> <p>Be aware of exits and recognise when to leave</p> <p>Stand up and calmly state the intention to leave</p> <p>Walk quickly towards the exit while keeping the aggressor within sight at all times</p>	<p><b>Stage 2</b></p> <p>Contact the police, if appropriate</p> <p>Seek medical attention if any physical injuries sustained</p>	<p><b>Stage 2</b></p> <p>Researcher contacts the nominated person immediately after the interview</p> <p>Researcher leaves contact sheet in secure Lancaster Box within two hours of the finish time to confirm actual time of leaving interview location.</p>

Step	Safety Precaution for Visit	Managing Aggression during Lone Working	Action following an Incident	Communication Procedure
3	<p>Set up code word to use in case of any danger.</p> <p>Give code word to nominated person</p> <p>Provide copy of Contact Sheet to the nominated person for each interview</p> <p>Keep loose change (coins) in case of no mobile phone reception at location</p>	<p>Stage 3</p> <p>Be prepared to call for external help by shouting 'fire' or 'call the police' very loudly.</p> <p>Stay in a lit-up environment</p> <p>Stay in a public and safe place</p> <p>Do not be alone</p>	<p>Stage 3</p> <p>Contact study supervisor at earliest opportunity</p> <p>Contact family to give re-assurance of safety</p> <p>Stage 4</p> <p>Work with the supervisors at earliest opportunity to try and identify how and why situation got out of control, and how to improve practice</p>	<p>Stage 3</p> <p>If the researcher does not make contact within expected time, the nominated person will ring the researcher to check welfare</p> <p>If researcher does not answer, nominated person will call Person 1 on contact sheet.</p> <p>Stage 4</p> <p>If nominated person still does not hear from the researcher and Person 1 is unaware of researcher's whereabouts, then Person 2 should be contacted.</p> <p>Stage 5</p> <p>If Person 2 is unaware of researcher's whereabouts, then Person 3 should be contacted</p> <p>Stage 6</p> <p>If Person 3 is unaware of researcher's whereabouts, then nominated person should call the police on 999 to advise of the situation</p>

## Appendix 14: Lone working contact sheet

ID	Personal Details	Emergency Contact Details (In order of priority)	Interview Details	Emergency Instructions for Contacting Emergency Persons
1	<u>Researcher</u>  Name:  Tel:  Address:	<u>Person 1</u>  Name:  Mobile no:  Home no:	Interview date:  Travelling by: Bus <input type="checkbox"/> Car <input type="checkbox"/> Other <input type="checkbox"/>  Departure time from home (estimated):  Arrival time at location (estimated):  Maximum duration: 2hrs  Departure time from location (estimated):  Actual time of departure from location:	<u>Stage 1</u>  Nominated person contacts the researcher if expected time is missed  Nominated person contacts person 1 first if researcher is unavailable  Nominated person will only contact persons 2 or 3 if person 1 is unavailable
2	<u>Study Supervisor 1</u>  Name:  Tel:	<u>Person 2</u>  Name:  Mobile no:  Home no:	<u>Location:</u>  Address:  Tel:	<u>Stage 2</u>  Nominated person contacts the police on 999 if Stage 1 is unsuccessful. Do not call location so as not to unnecessarily distress the participant
3	<u>Study Supervisor 2</u>  Name:  Tel:	<u>Person 3</u>  Name:  Tel no:		

