Caregiver wellbeing and the role of resilience in seeking support when caring for an individual with Dementia.

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Abstract

Background & aims: To provide appropriate and suitable support to caregivers of people with dementia, it is important to explore the risk and protective factors related to their psychological wellbeing. The aim of this thesis, is firstly, to highlight lived experiences of dementia caregiver's; secondly, to explore the role of psychological resilience in their ability to adapt and maintain their role; and finally, to identify and examine their perspectives of current support services in meeting their needs.

Method: A sequential explanatory mixed method design was used. In Phase I participants completed a postal survey (*n*=45), including demographic information, a health-related quality of life measure and a psychological resilience scale. Results were used to inform and direct Phase II, in which semi-structured interviews were conducted (*n*=11), transcribed and analysed using thematic analyses.

Results: The quantitative findings indicated that participants with higher mental health outcomes and high psychological resilience were more likely to access support services. Physical wellbeing had a greater association with factors related to providing care. Seven main themes were identified in the qualitative analysis, the majority relating strongly to a high degree of restricted opportunities and encroaching responsibilities. The findings indicate that caregivers are required to be flexible and adapt to their individual circumstances, within an ever-evolving situation.

Implications: The results of this study suggest that identifying those with low levels of psychological resilience and wellbeing may be useful in identifying those in greater need of support. Recommendations for potential service developments are discussed, as well as the implications for Counselling Psychology practice.

Key words: dementia, caregivers, seeking support, wellbeing, psychological resilience

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Chapter 1

Introduction

1.1. Thesis outline

The series of paragraphs below set out a brief overview of the chapters that comprise this doctoral thesis. The summaries are aimed at highlighting key topics and subject areas that comprise the present study.

Dementia is regarded as a worldwide phenomenon and a "global public health challenge" (World Health Organisation; WHO, 2012, p. 4)". The first chapter explores key, relevant aspects of dementia as the context for the present research project. In this study, the terms 'dementia', 'caregiver' and 'care recipient' are used throughout and will be defined.

Chapter two presents a systematic review of the literature on the experiences of caregivers of people with dementia (PwD), with a focus on the impact that providing support may have on their wellbeing and level of psychological resilience; as well as examining caregivers perspectives on access and use of support services. It goes on to outline and discuss the current methodological approach which had two phases; a quantitative examination which then informed on the qualitative investigation of a sub-population. This will include the rationale for introducing the concept of psychological resilience as an alternative perspective on caregiver wellbeing. There is also a role for recognising the value of how a research project is a constructed entity and the implication of the researcher's own position being monitored for influence on the study.

The third chapter presents the first phase methodology and results. This covers the postal survey approach, which provides a broader investigation across a wide population, and the quantitative outcomes which then form the basis for the second phase of this study.

The fourth chapter builds upon the findings of Phase I (see above) and presents the methodology and results. This approach looked at a sub-set population from Phase I, to explore a more in-depth experience of being a caregiver; utilising a qualitative method.

Chapter five brings together the findings from across the two phases and discusses implications for future research and clinical practice. The strengths and limitations of the study are considered, alongside recommendations for development of dementia services.

A critical appraisal is presented in chapter six. This is a reflective evaluation of the research process and of the development of the investigator, as a scientist-practitioner. This aims to capture the ontological and epistemological concerns for research through this mechanism.

The thesis finishes with a section for references, followed by the appendices.

1.2. Research context: Dementia

The present research study explores the experiences of caregivers of PwD and in order to appreciate the issue faced by caregivers it may be useful to offer a context, initially, on key relevant aspects of dementia.

Dementia is a progressive, degenerative neurological condition and is classed as a syndrome or a grouping of symptoms which manifests in a variable combination (Arendt and Jones, 1993; The National Institute of Health & Care Excellence [NICE] & Social Care Institute for Excellence [SCIE], 2007). Although disorders of the dementia type are most common in later life, it is adamantly professed that it is not a normal part of ageing (Graham & Warner, 2009). Manifestation and progression of symptoms are dependent on the type of syndrome, neurological area affected and indicated prognosis (McKeith & Fairbairn, 2001). In some cases, progression may be labelled as mild, moderate or severe, this is dependent on the dementia syndrome (Arendt and Jones, 1993).

1.2.1. Definition

From the research literature, it is considered that dementia is characterised by a deterioration in cognitive functioning from a previous level, accompanied by a decline in personal and social functioning and, in many cases, behavioural and psychiatric disturbances (Dementia UK, 2015; Graham & Warner, 2009; McKeith & Fairbairn, 2001; NICE & SCIE, 2007). Due to the interplay of both health and social care in identifying, treating and providing care and support for dementia, each perspective may provide contrasting approaches and viewpoints (NICE & SCIE, 2007). Several formal definitions of dementia exist, such as the International Classification of Diseases, Version 10 (ICD-10; WHO, 2004):

> "a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviours or motivation" (p. 28).

The Department of Health (DoH) provide the following definition within 'A National Dementia Strategy' (2009):

> "The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness" (p. 15).

The importance of accurate diagnosis in differentiating between different syndromes from onset, presentation of features and course, has become more precise over the last three decades (McKeith & Fairbairn, 2001). This has led to the development of more precise clinical features that are used to identify dementia syndromes (McKeith & Fairbairn, 2001). As with the definition, the criteria to classify and diagnose dementia with clarity is also problematic (Kitwood, 1987). Furthermore, the majority of presentation features overlap and, therefore, single causality cannot be assumed (Kitwood, 1987).

1.2.2. Operationalised criteria

Dementia is essentially a descriptive term which can encompass several specific underlying aetiologies (Stokes, 2007). The most common type of dementias reported, that are primarily cortical in nature, are Dementia of the Alzheimer's type (DAT; Andrews, 2015; Graham & Warner, 2009; McKeith & Fairbairn, 2001; Morris, 2008; Pulsford & Thompson, 2013), Vascular Dementia (VaD; Andrews, 2015; McKeith & Fairbairn, 2001), Dementia with Lewy Bodies (DLB; Hohl, Tiraboschi, Hansen, Thal & Corey-Bloom, 2000; McKeith & Fairbairn, 2001; Morris, 2008) and Fronto-temporal Dementia (FTD; Graham & Warner, 2009; Morris, 2008; Pulsford & Thompson, 2013). Figure one shows the approximate percentage of current cases that have been diagnosed with a specific dementia type in the United Kingdom (UK; Alzheimer's Research UK, 2018a).

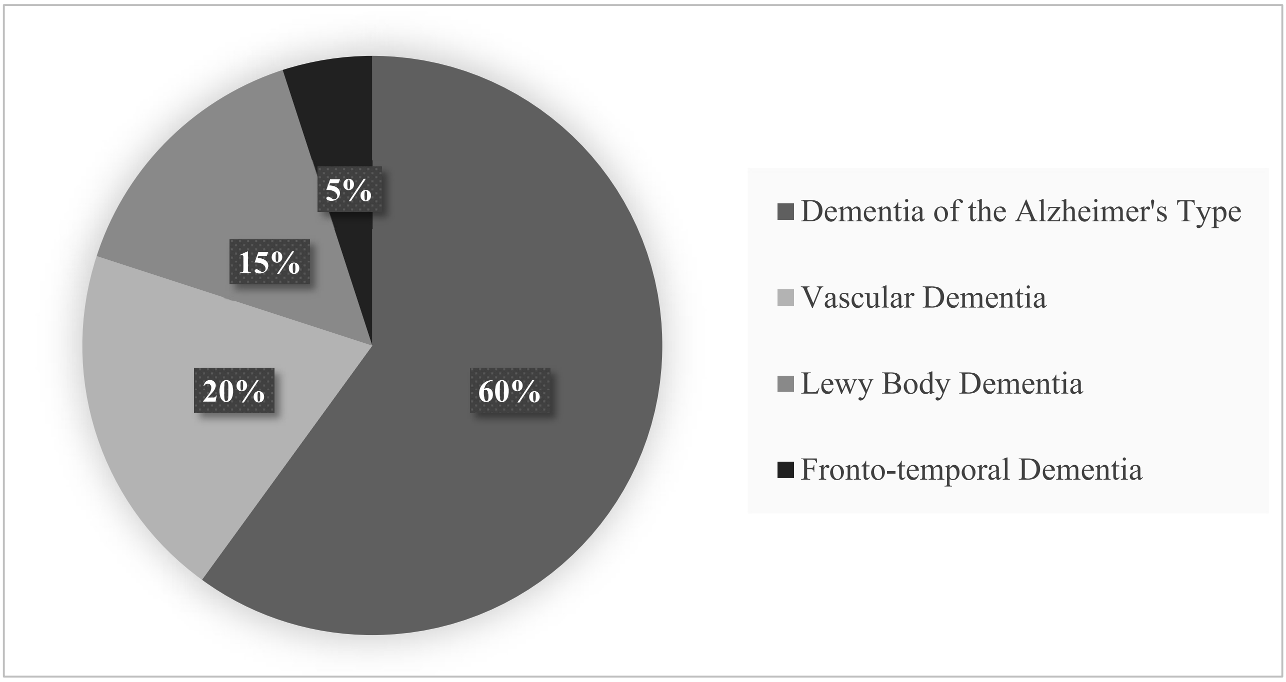

Figure 1. Percentage of cases related to specific Dementia Types.

In order to differentiate and exclude alternative possibilities, the diagnostic process requires a set of characteristics and symptoms, in order to provide a practical description of a person’s presentation and prognosis of illness (Stokes, 2007).

The ICD-10 (WHO, 2004) is most commonly used to diagnose dementia in the UK and is broadly similar to the Diagnostic and Statistical Manual, Version 4 (DSM-IV; American Psychiatric Association [APA], 1999) used in the United States of America (USA; McKeith & Fairbairn, 2001); prior to the release of the fifth version of the DSM (DSM-V; Gray, 2013). Additional specific standards to the current general diagnostic criteria (WHO, 2004; see Appendix A), are suggested to recognise and diagnose different dementia syndromes (McKeith & Fairbairn, 2001).

1.2.3. Assessment and diagnosis

The NICE-SCIE guideline on ‘supporting people with dementia and their carers in health and social care’ (2007) recommended that a comprehensive assessment should take place in order to diagnose dementia. The guidance states that this should include taking a history, a cognitive and mental state examination, physical examination, and other appropriate investigations. It should also include a medication review, use of structural neuroimaging equipment, and referral to a specialist or memory assessment service; in order to exclude any other pathologies and help establish the diagnosis (Graham & Warner, 2009; Pulsford & Thompson, 2013).

Continual improvements in clinical definitions and diagnostic criteria of dementia syndromes have enabled clinical practitioners to be more accurate (Baldwin & Capstick, 2007; Howcroft, 2004). Kitwood (1999) argued, however, that diagnosing dementia accurately remains difficult, despite improvements in diagnostic techniques (Morris, 2008). A survey conducted by Turner and colleagues (2004), showed that one-third of General Practitioners (GPs) reported limited confidence in their diagnostic skills with regards to dementia and believed it to be within a specialist domain, rather than housed within general practice (Turner, et al., 2004).

Despite the developments with diagnostic parameters and the difficulties that remain, there is an increasing pressure towards providing an early diagnosis for people with a suspected dementia syndrome (DoH, 2009; Howcroft, 2004; Luengo-Fernandez, Leal & Gray, 2010; Turner, et al., 2004). The procurement of a ‘timely diagnosis’ supports the person with dementia and their families to engage with support services and plan for their respective futures (DoH, 2009; Graham & Warner, 2009; Howcroft, 2004; Pulsford & Thompson, 2013; Turner, et al., 2004). Without a diagnosis, it is more difficult to access social services support and receive suitable pharmacological (Andrews, 2015; Howcroft, 2004), psychological and psycho-social interventions (Alzheimer's Disease International [ADI], 2011; Howcroft, 2004).

Once a diagnosis has been confirmed, this provides the opportunity for professionals to offer an integrative approach that encompasses assessment, diagnostic, therapeutic, and rehabilitation services; provided alongside local health, social care and voluntary organisations (NICE-SCIE, 2007), to the PwD and their families. Services, however, do vary across locations and for population estimations (Graham & Warner, 2009).

Despite evolving diagnostic criteria and a recognition of the importance of early diagnosis, research indicates that most people living with dementia have not received a formal diagnosis (ADI, 2011). When compared on an international basis, the UK's level of diagnosis and treatment is generally low, with only about one-third of individuals with dementia receiving a formal diagnosis (DoH, 2009). This gap in treatment can increase the distress for the PwD and their family caregiver, if they are unable to access support only available for those who have sought and received a diagnosis (ADI, 2011).

1.2.4. Impact of dementia

Currently dementia affects around 850,000 people in the UK (Alzheimer's Society, 2017). It is estimated that by the year 2025 over a million people will be affected by dementia and this will increase to two million by 2050 (Alzheimer's Research UK, 2018b). The majority of PwD live in the community supported predominantly by close friends or family, usually known as informal or familial caregivers (Alzheimer's Society, 2012). Informal caregivers support others who are having difficulty because of either, or a combination of, a physical, cognitive or emotional impairment and are not usually financially compensated for their services (Vitaliano, Zhang & Scanlan, 2003).

Most people prefer to be cared for in their own home (Royal Surgical Aid Society [RSAS] & Association for Dementia Studies, University of Worcester [ADS], 2016). Informal caregivers provide a free available resource that allows two thirds of PwD to live in the community, compared to the other third of the population that live in a care home (Alzheimer's Society, 2012; National Audit Office [NAO], 2007). A report commissioned by the Alzheimer's Research Trust, compared the costs of dementia and other chronic diseases (cancer, stroke and coronary heart disease) with national expenditure on research (Luengo-Fernandez, et al., 2010). They concluded that dementia is the "greatest economic burden" (p. 7), and accounts for over 50% of the combined health and social care costs of the other chronic diseases included in the study; yet, only receives 6% of the research funding.

Currently, the estimated cost of dementia in the UK is £26 billion, in terms of health and social care, informal care and productivity losses, with the expectation that this will double by 2040 (Alzheimer's Research UK, 2018c). Informal caregivers provide a financial benefit to health and social care as they save the UK over £11 billion a year (Alzheimer's Society, 2017), it is, therefore, of benefit to health and social services to ensure that the caregiver continues their role within the home environment. There are approximately 700,000 caregivers of PwD in the UK (Alzheimer's Research UK, 2017), and this number is also set to increase alongside cases of dementia.

1.3.Research context: Caregiver

Having provided a context of dementia, it is then important to set out key relevant aspects in relation to providing care and its impact on caregivers.

1.3.1. Defining caregiver

There is currently no "single definition" of the term caregiver (Clements, 2012, p. 7), confused further by the wide-ranging variations used in the literature (Clements, 2009; Payne, 2007; Schoenmakers, Buntinx & Delepeire, 2010). There is, however, wide consensus around the terminology used for describing family members who provide care and support to a loved one with dementia.

References are made to family members or close relatives, described as carers or caregivers, who offer their support mainly through circumstance or an emotional attachment (Brodaty & Berman, 2008). They can often be referred to as 'informal caregivers', to distinguish them from 'formal' paid care workers (Clements, 2012; Payne, 2007). A set of descriptions of caregiver that can be found in the literature are summarised in Table 1.

The wide use of descriptors and lack of agreement of a definition is difficult and requires some form of operationalising in order to characterise the parameters of the term caregiver.

1.3.1.1. Definition of caregiver

For this study, the definition of caregiving offered by Zarit and Edwards (2008) is used, as it encompasses most of the descriptive points, see Table 1. It also reflects the fluctuating interactions necessary to provide care to a loved one for their own independent living:

> "A relationship develops into caregiving when an older person becomes dependent on another's help to complete tasks and another family member (e.g. spouse or child) provides or arranges for this assistance. In other words, caregiving constitutes a change in ongoing patterns of exchange in response to a new disability, which results in one or more people providing regular help to the elder" (p. 256).

1.3.1.2. Primary vs secondary caregiver

Another important distinction is usually made between 'primary' and secondary' caregivers. Major responsibility is assumed for the PwD in the former; whereas, occasional assistance or periodic relief is offered, especially around specific care tasks in the latter (Brodaty & Berman, 2008; Hudson & Payne, 2009; Zarit & Edwards, 2008;). For the purposes of this study, the emphasis has been to identify and use the 'primary' caregivers in order to avoid the complexity of this issue. This could be addressed in any future research by comparing the relevant research issues across the two groups.

Table 1

Summary of caregiver descriptors

- A person who provides or intends to deliver a substantial amount of care[1] on a regular basis (Clements, 2012; DoH, 2009).
- They do not provide or intend to deliver care by virtue of a contract or as a voluntary placement (Clements, 2012; DoH, 2009).
- They are not paid or employed to deliver care to their loved one (Clements, 2012; Greutzner, 2001; Morrison, 2008).
- They have had no formal training (Marriott, 2009) and are non-professionals (Morrison, 2008).
- They provide a broad range of assistance that can include: physical, social, medical and emotional / psychological support, advice or advocacy (Clements, 2012; Gibson, Kelly & Kaplan, 2012; Hudson & Payne, 2009).
- Any person with a significant personal relationship, usually family, friends or neighbours (Clements, 2012; Gibson, et al., 2012; Hudson & Payne, 2009).
- They may or may not co-habit with the person receiving care (Hudson & Payne, 2009).
- Provides care to a person with a chronic, disabling or life-threatening condition (Gibson et al., 2012; Hudson & Payne, 2009).

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[1] Care is defined as the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something (Oxford University Press, 2017).

The term 'care recipient' (CR) is used to denote those individuals with a diagnosis of dementia, who are in receipt of care and dependent on another's support to complete tasks (Zarit & Edwards, 2008).

1.3.2. Providing care

The transformation of dementia care over the last three decades has highlighted the vulnerabilities of what Kitwood termed the 'standard paradigm' and initiated the movement towards an idea of 'person-centred care' for those with dementia and their families (Baldwin & Capstick, 2007; Kitwood, 1999). Since the 1980s research into the 'hidden victims' of dementia has increased exponentially, focussing on the negative aspects of providing care (Dickinson, et al., 2017) and on the effectiveness of interventions to reduce or prevent these effects (Pot, 2004).

The recognition of caregiver's commitment to their caregiving responsibilities have been slow-going over the last few decades. The development of legislation that recognises the importance of their needs, separate from the person with the illness, was started in the 1960s by the carer's movement (Carers UK, 2016). Legal recognition that secures rights and protection for caregivers in the UK, however, only came about in 1996 (Carers UK, 2016). This has expanded and has led to improved financial support and protection from discrimination (Carers UK, 2016).

The development of an integrated way of working, a partnership between the PwD, their caregiver, and health and social care services, is vital (National Health Service [NHS] Confederation, 2016); as the majority of support is offered by family caregivers, usually within the home (Pot, 2004; Pulsford & Thompson, 2013).

1.3.3. Support and interventions for caregivers

Support and interventions for caregivers have been designed and developed with the aim of reducing the adverse outcomes of providing care, as well as sustaining their ability to look after their CR within the community (NICE & SCIE, 2007; RSAS & ADS, 2016; Sörensen, Duberstein & Pinquart, 2006).

1.3.3.1. Support Services

The main sources of support for PwD and their families include; services provided by the NHS, social services, private companies, charities and not-for-profit organisations (Alzheimer's Society, 2015). These services, however, cover a multitude of conditions and are non-specific. Several organisations exist to support all caregivers; namely Carers UK that have also had an influence on supporting the rights of carers throughout its history (Carers UK, 2016). Other charitable organisations exist specifically to support PwD and their caregivers, namely, the Alzheimer's Society and Dementia UK (Alzheimer's Society, 2012; Dementia UK, 2015). A further valuable source of support are the services provided by the Admiral Nurses Service (Dementia UK, 2015; Raminder & Thompson, 2008). Admiral Nurses are specialist dementia nurses who provide practical and clinical input, as well as one-to-one direct care for the PwD and their family (Dementia UK, 2015).

In order to promote best practice, when working with individuals affected by dementia, clinical guidelines are recommended to the individual concerned and their care providers (NICE & SCIE, 2007). These are outlined in Table 2.

In general, the majority of formal support services for family caregivers include day centres and respite care for the CR (Dementia UK, 2013; Manthorpe, Iliffe & Eden, 2003). Further support includes carers groups, information from charitable agencies, social services, and financial benefits; the latter aims to alleviate financial losses associated with prolonged provision of care (Manthorpe et al., 2003).

Table 2

Clinical guidelines

Individual with dementia	Dementia caregiver
• Providing information on signs, symptoms and prognosis of the condition, • Practical support, • Medical treatment, • Medico-legal issues, and • Personal support.	• Assessment of caregiver’s needs, • Peer support groups, • Training courses, • Provision of transport services, • Access to respite and short-break services, and • The offer of psychological therapy.

1.3.3.2. Support interventions

The majority of evidence on interventions for dementia caregivers suggests the benefits of promoting psychological wellbeing and good health (Dickinson, et al., 2017; NICE & SCIE, 2007; Sörensen, Pinquart & Duberstein, 2002), however, research on the effectiveness of interventions is contradictory (Baldwin & Capstick, 2007; McKinnon, O’Connor, Savage, Hodges & Mioshi, 2013). Yet, support services have been established to provide caregivers with interventions designed to increase education, training and support to enable them to look after their CR within a home environment (NICE & SCIE, 2007).

A recent comprehensive literature review has been published on ‘The experiences, needs and outcomes for carers of people with dementia’ (RSAS & ADS, 2016). Within this review, several characteristics of successful interventions were indicated. This included multicomponent interventions that were tailored to the needs of the CR, the caregiver and care dyad, providing a range of possible processes e.g. self-care strategies. These were provided by skilled and experienced practitioners, as well as being designed to address the development of coping strategies and the enhancement of psychological resilience. It was also pointed out that the studies reviewed, highlighted the challenges associated with the methodologies and the real-life translation into clinical practice (RSAS & ADS, 2016).

1.4. Conclusion

Dementia is currently attracting a global range of interest, albeit not surprisingly, as it has become widely acknowledged that the number of ageing people in the population is increasing, due to advances in healthcare, awareness, and adoption of healthier lifestyles and exercise (WHO, 2012). Dementia is one of the major causes of disability and dependency among older people and is set to increase (Innes, Morgan & Kostineuk, 2011; WHO, 2012). This has wide economic implications (Alzheimer’s Research UK, 2018c; NAO, 2007, 2010; NICE & SCIE, 2012), as well as consequences for health and social care. This will then lead to an increasing need for appropriate care with a growing pressure on family caregivers (Droës, et al., 2004; Pot, 2004; WHO, 2012). Currently, the exact scope and future cost of dementia care is unknown, due to the large amount of informal care provided by family caregivers (Bauer & Sousa-Poza, 2015; NICE & SCIE, 2007; Payne, 2004). This is further exacerbated by the unknown number of people who have not received a diagnosis (ADI, 2011; DoH, 2009).

Understanding the caregiving experience and factors related to the context of dementia care will allow support services to “engage with individuals in a way that respects, and works in partnership with, individual understandings of their own care needs” (Clarke, 2001, p. 97), which could lead to channelling resources into services and key requirements for these caregivers.

Chapter 2

Systematic Review

2.1. Introduction

It has been proposed that caring for an individual with dementia exists within a different context; compared to other disabilities and chronic conditions, for example, cancer, stroke and mental health (Greutzner, 2001; Pulsford & Thompson, 2013; Sistler, 1989). Becoming the caregiver of a loved one after an unexpected event requires adaptation and involves engagement in a situational transition (Pereira & Botelho, 2011). Responsibilities, commitments and role expectations are often assumed within this emerging process, whereby the caregiver may find themselves immersed in the world of providing care to an increasingly dependent loved one (Payne, 2004; Pereira & Botelho, 2011).

Furthermore, a higher emphasis is placed on cognitive decline, rather than physical disability – although this may develop as the condition progresses – which may result in dementia caregiver's experiencing higher levels of anxiety, burden and strain (Georges, Jansen, Jackson, Meyrieux, Sadowska & Selmes, 2008; WHO, 2012). This may be due to the following: the nature of the changing relationships between caregiver and CR; the progressive and gradual decline of the condition; and, the inevitable loss of the known character of the CR (Ingebretsen & Solem, 1997). Providing care to a PwD is, therefore, suggested to be more challenging to manage than practical burdens (Ingebretsen & Solem, 1997), such as, support with activities of daily living (ADL's; i.e. food preparation and dressing appropriately), and assistance with instrumental activities (i.e. personal finances and shopping; WHO, 2012). This is further exacerbated if the CR displays behavioural symptoms or 'challenging behaviour' (Maciejewski, 2001), also referred to as 'behavioural and psychological symptoms in dementia' or BPSD (Bird & Moniz-Cook, 2008); which is suggested to be the largest contributing factor to caregiver burden (CB; Etters, Goodall & Harrison, 2008), rather than the CR's degree of cognitive impairment (Rosdinom, Zarina, Zanariah, Marhani & Suzaily, 2013).

There is, therefore, a recognition that dementia caregivers have increased vulnerabilities and risk factors associated with developing psychological distress (Cherry et al., 2013; Droës et al., 2004; Santin, Treanor, Mills & Donnelly, 2014; WHO, 2012; Zarit & Edwards, 2008), as well as difficulties that have an impact on their physical health (Brown & Brown, 2014; Silverberg Koerner, Kenyon & Shirai, 2009). The experiences of dementia caregivers are unique and significantly different from traditional caregiving (Pot, 2004; RSAS &ADS, 2016), as they are required to negotiate a fluctuating situation that may be ambiguous at best (Ingebretsen & Solem, 1997). Since the 1980s, the majority of research in dementia care has primarily focussed on stress, caregiver burden, depression and the negative experiences of providing care (Dickinson et al., 2017; Keeling, Dolbin-Macnab, Hudgins & Ford, 2008; Sanders, Ott, Kelber & Noonan, 2008; Woods, 2008; Zarit & Edwards, 2008). CB has especially been a dominant theme in the literature (Keeling, et al., 2008), and can be defined as:

> "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience" (Kasuya, Polgar-Bailey &Takeuchi, 2000, p. 119).

In order to understand the dementia caregiving experience, the initial focus of research was placed exclusively on the provision of care and the burden as a consequence (Keeling, et al., 2008; Sanders, et al., 2008). This experience has been understood from exploring models of stress and coping. Of the models of care that have been proposed in this research area, the most prevalent model in use to-date, is called the 'transactional model of stress and coping' (Dickinson et al., 2017; Lazarus & Folkman, 1984; Papastavrou et al., 2011). The measurement and definitions of terms such as 'CB' and 'distress' within the literature, however, are inconsistent (Duijnstee, 1993; Toates, 1995). Thus, the caregiving experience has been negatively evaluated and promoted, unintentionally, as harmful to the caregiver, which for the most part is unjustified (Brown & Brown, 2014). More recently, the focus has evolved to include the importance of the relationship between the caregiver and CR and the positive outcomes of the caring experience (Clarke, 2001; Howcroft, 2004).

With the introduction of the positive psychology movement, a recent shift has occurred from focussing on negative outcomes to positive states within the caregiving experience (Bayne, 2012; Burns, Anstey & Windsor, 2011; Dickinson et al., 2017). Recent research has highlighted that some caregivers adapt and adjust more successfully to the caregiving experience than others (Donnellan, Bennett & Soulsby, 2015; Joling et al., 2017; RSAS & ADS, 2016; Wilkinson & Campbell, 1997). This positive outcome approach can be seen in recent literature, relating to interventions that support family caregiving, which increasingly emphasise building and strengthening caregivers existing capabilities, instead of only reducing their difficulty (Dickinson et al., 2017; RSAS & ADS, 2016).

The outlook from a stress and coping model may, therefore, be in need of some revision (Brown & Brown, 2014). This leads to an alternative perspective being suggested, based on the concept of psychological resilience;

> "The rationale for examining resilience phenomena rests on the fundamental assumption that understanding how individuals overcome challenges to development and recover from trauma will reveal processes of adaptation that can guide intervention efforts with others at risk …" (Masten, 2001, p. 8; cited in Wilks & Croom, 2008, p. 364).

2.1.1. Purpose & aims of systematic review

Within the literature on dementia caregiver's, much of the research has focussed on describing the emotional and psychological difficulties that these individuals experience, with little research directly assessing whether these needs are being met (Patterson, Pearce & Slawitschka, 2010). Relatively few studies have focused on the role of psychological resilience in seeking support, when caring for a PwD; even though it is a recognised that the ability of caregiver's to adapt, adjust and cope with the caring experience is hugely varied (Ingebretsen & Solem, 1997; Miesen, 2006; Zarit & Edwards, 1998). This area of research is important, as it will allow for a more detailed understanding of how caregivers perceive, experience and express their needs (Patterson et al., 2010); and it will, hopefully, enable support services to better meet their needs.

The aim of this chapter is to review the literature on the experiences of caregivers of PwD and the impact that providing care may have on the caregiver's psychological wellbeing. In addition, the review aims to discuss the positive outcomes of the caregiving experience, more specifically the role of psychological resilience in providing dementia care; as well as, examining caregivers perspectives on access and use of support services.

2.2. Method

To identify relevant studies relating to the purposes of this review, a computerised literature search was carried out.

2.2.1. Search strategy

Keyword searches were undertaken using electronic databases for studies published between 2008 – 2018, and included the following databases: PsychINFO, Medline and the Cumulative Index to Nursing and Allied Health Literature (CINAHL).

The key terms *(care* and dementia)* were used with a combination of the following search terms: *(stress and coping and psycholog* wellbeing) and (burden) and (resilience or resiliency or resilient) and (adaptation and resources) and (positive outcomes or experiences or aspects) and (physical wellbeing or physical health) and (mental wellbeing or mental health) and (seeking support and intervention* and perspectives or views or perceptions or attitudes or opinions).*

The reference lists of articles selected to be included in the present review were manually searched to identify additional sources, not identified in the database search. Similarly, with the studies identified above, titles and abstracts were screened to assess relevance in accordance with the selection criteria (see Table 3).

2.2.2. Selection criteria

The selection criteria used in this systematic review are outlined in Table 3.

Table 3

Selection criteria

Inclusion criteria	Exclusion criteria
• English language or articles translated into English	• Duplicated articles • Not in the English language
• Peer reviewed	• Not peer reviewed
• Full text available	• Full text unavailable
• Published after 2008	• Published before 2008
• Care recipient must have a diagnosis of dementia	• Care recipient does not have dementia (e.g. Mild cognitive impairment)
• Providing care in the community	• Care is not provided in the community
• Care provided by family member (primary caregiver)	• Care is not provided by a family member
• Empirical research	• Non-empirical research e.g. systematic reviews, case studies

2.2.3. Search results

Following the selection procedure, sixty studies met the inclusion criteria and were included in the present review. Figure 2 provides a summary of the (literature) selection process.

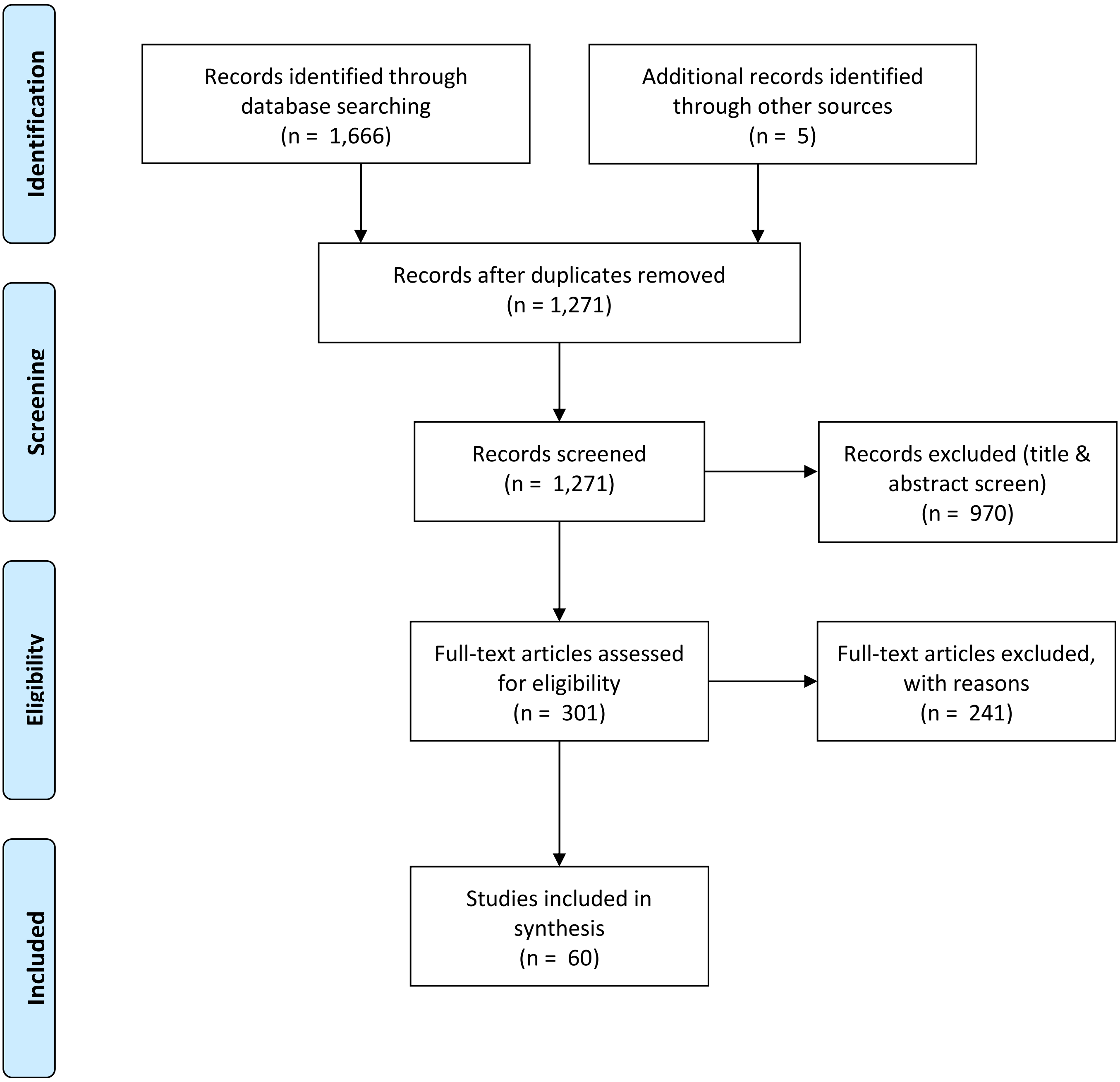

Figure 2. Selection process flow diagram.

2.2.3.1. General study characteristics

From the sixty studies selected, the majority were cross-sectional in design (*n*=54) and the remaining studies longitudinal (*n*=5). One article reported on two studies, the first being cross-sectional in design and the second longitudinal. Two studies used mixed-methods, 49 were quantitative and 9 utilised qualitative methodology.

The included studies originated from a wide variety of countries, including the USA (*n*=18), UK (*n*=4), Australia (*n*=4), Spain (*n*=4), Norway (*n*=2), Sweden (*n*=2), The Netherlands (*n*=2), Germany (*n*=2), Turkey (*n*=2), Canada (*n*=2), Japan (*n*=2), China (*n*=2), South America (*n*=2), and one each in Belgium, Republic of Ireland, Portugal, Greece, Finland, Cyprus, Thailand, Republic of Korea, Czech Republic, Hong Kong, and South Africa. One study combined information from two countries, The Netherlands and the UK.

Sample sizes ranged from 7 to 44 participants in the qualitatively designed studies and 25 to 1,048 for the quantitative methodology. Most studies reported a mean age for caregivers, which ranged from 51 to 79 years. Seven studies did not provide mean age or age ranges for their participants. The percentage of female participants ranged from 25 to 100 per cent, although two studies only included husbands, and one study did not report gender. Fifteen of the studies only included spousal caregivers as participants, three studies only recruited adult child caregivers (ACC), whereas the remaining studies included all primary caregiver's who looked after a PwD. The majority made a distinction between spouse and non-spousal caregiver's. Whereby, non-spouse could incorporate ACC's, siblings, children-in-law, mostly daughters-in-law, friends and other family relatives.

The majority of studies included did not differentiate between different types of dementia. Most specify dementia (*n*=30) or clarify a diagnosis of DAT (*n*=7). Eleven articles provided no details regarding diagnosis or type of dementia. One study focussed on FTD and the remaining articles (*n*=11) provided a breakdown of different dementia types, including DAT, VaD, FTD, LBD, mixed and other.

A summary of studies included in this review can be found in Appendix B.

2.2.4. Assessment of research quality

The quality of the included papers were assessed using the 'Standard quality assessment criteria for evaluating primary research papers from a variety of fields' (Kmet, Lee & Cook, 2004). The studies were evaluated based on their two scoring systems: one for quantitative research reports (14 criteria) and one for qualitative (10 criteria). For a breakdown of scoring parameters, see Appendix B.

Overall, articles performed well on providing clear description of content and response options for measures used, specifying clear predictors and outcome measures, as well as reporting clear results. Some studies performed poorly on describing participant selection parameters, having small sample sizes and providing a clear description of the sample population, with a few lacking details on age, gender, dementia type and relationship to the PwD.

2.3. Synthesis

Studies included in this review considered a range of search criteria related to family caregiver's experiences of providing care to a PwD. To support a narrative synthesis of the findings, the articles were grouped into three themes, namely 'providing care', 'appraisal of the caregiving experience' and 'engagement with services'. Each theme has been further subdivided into categories.

2.3.1. Providing care

The majority of studies included in this review have examined the experiences of dementia caregivers, including providing care to a PwD, their ability to maintain their role and the impact of CB. Furthermore, they have attempted to identify and explore predictors and protective factors of stress and burden in dementia caregiving.

2.3.1.1. Maintaining the caregiving role

Twelve studies explored different elements of understanding the caregiving role. This included specific investigations around caregiver and CR relationship type and quality, gender differences and caregiver's use of coping strategies.

The research has mainly been explored from a spousal perspective (Baker, Robertson & Connelly, 2010; Knutsen & Råholm, 2009; Kraijo, van Exel & Brouwer, 2015; Meyer, Mc Cullough & Berggren, 2016; Sanders & Power, 2009; Yoshioka, Yamamoto, Yasuda, Saijo & Kishi, 2013). It is suggested that spouses have unique relationships and can, therefore, potentially experience greater adversity in terms of loss, grief and the changes that occur in terms of their roles, responsibilities and relationships as they provide care (Baker, et al., 2010; Meyer, et al., 2016; Nay, Bauer, Fetherstonhaugh, Moyle, Tarzia & McAuliffe, 2015; O'Rourke, Kupferschimidt, Claxton, Smith, Chappell & Beattie, 2010; Sanders & Powers, 2009; Yoshioka, et al., 2013).

A study by Yoshioka, et al. (2013) suggested that as spouses are more familiar with the pre-morbid personality, history and behaviour of their loved one, they are better able to negotiate difficult behaviours and modify their environment and interactions accordingly. A greater emotional and relational bond with the CR, however, could increase the distress experienced by caregiver's (Lee, Sohn, Lee, Seong, Park & Lee, 2017). This could be as a result of the everyday life of caregiver's changing gradually in line with the CR's declining symptoms (Meyer, et al., 2016). The studies reported that caregivers go through a transitional period of loss, with some adapting better to their caregiving role than others (Nay, et al., 2015).

The use of coping strategies has also been explored in the literature and might be another factor that influences caregiver's to maintain their role. Emotion-focussed coping was related to higher overall reports of anxiety, depression, burden and poor health status, compared to caregivers who are more likely to employ problem-focussed coping (García-Alberca, et al., 2013; Papastavrou, et al., 2011; Snyder, et al., 2015). Williams, Morrison and Robinson (2014) found that caregivers were more likely to use a range of coping techniques dependent on their appraisals of the circumstances. Participants in their study reported that they mainly adopted active and information seeking techniques to manage current difficulties and increase their sense of control, however, they used active avoidance strategies when considering future prospects of continuing their caring role or when feeling helpless.

The role of gender has also been explored as significant to understand the management of caregiver strain and lived experiences (Baker et al., 2010; Knutsen & Råholm, 2009; Sanders & Power, 2009). Women were found to be more likely to use emotion-focused coping strategies, such as wishful thinking (Papastavrou, et al., 2011; Snyder, et al., 2015), whereas, men were found to be more likely to use problem-focused coping strategies, such as acceptance, (Snyder, et al., 2015). Men are also less likely to communicate their thoughts and feeling with others or seek support; accepting it as a 'last resort', when they had depleted their own strength and capacity to provide care (Baker et al., 2010; Knutsen & Råholm, 2009; Sanders & Power, 2009).

Overall, from this research, relationship quality, gender differences, and adjustment to changing roles and circumstances have been highlighted as important aspects to consider when supporting caregivers

2.3.1.2. Predictors and protective factors of caregiver burden

Understanding the difficulties that caregivers face has been a main research aim in dementia research, in order to develop intervention approaches to support caregivers to continue to provide care as long as possible and delay the need for the CR to go into long-term care (Ask, Langballe, Holmen, Selbæk, Saltvedt & Tambs, 2014; Cucciare, Gray, Azar, Jimenez, Gallagher-Thompson, 2010; Yilmaz, Turan & Gundogar, 2009). Twenty-eight articles explored predictive and protective factors of CB, as well as related concepts, such as stress, burnout and the impact on mental health aspects.

The majority of studies explored different characteristics as determinants of CB. The findings of several studies indicate that, the following CR characteristics may contribute significantly to higher levels of CB and emotional distress over time, such as CRs cognitive functioning, behavioural symptoms (BPSD; Ervin, Pallant & Reid, 2015; Hall, et al., 2014; Liu, et al., 2017; Mausbach, et al., 2012; van der Lee, Bakker, Duivenvoorden & Dröes, 2017), their ability to self-care (Yilmaz, et al., 2009), sub-types of dementia (i.e. FTD, LBD & DAT; Bristow, Cook, Erzinclioglu & Hodges, 2008; Liu, et al., 2017; Wang, Xiao, He, Ullah & De Bellis, 2014), moderate to severe diagnosis of dementia (Hall, et al., 2014; Kršiková & Zeleníková, 2018), changes in the CR's level of functioning (Razani, et al., 2014), increased dependency of daily tasks (Braungart Fauth, Femia & Zarit, 2016; Hall, et al., 2014), and increased supervision (van der Lee, et al., 2017).

It is suggested that the severity of CR behavioural problems contribute to increased psychological distress, more so than CR's cognitive functioning (Mausbach, et al., 2012; van der Lee, et al., 2017). The literature suggests that stress experienced by caregivers, or increased levels of CB, may diminish personal resources and enhance maladaptive responses, thus, resulting in higher incidences of depressive symptoms (Mausbach, et al., 2012).

Other potential predictors of CB, investigated by the research literature, are factors related to caregiver characteristics. These included the caregivers' ways of coping, mental health symptoms, for example depression and anxiety (Liu, et al., 2017; Yilmaz, et al., 2009), being the primary caregiver (Solberg, Solberg & Peterson, 2014), the reporting of financial burdens (Ducharme, Kergoat, Coulombe, Lévesque, Antoine & Pasquier, 2014; Flynn & Mulcahy, 2013), unmet support needs, feelings of isolation, decreased mood states, the impact on their social activities, changes in the relationship with their CR, adopting new roles and, lack of knowledge on dementia and available support services (Ducharme, et al., 2014; Flynn & Mulcahy, 2013; Quinn, Clare, Pearce & van Dijkhuizen, 2008; Schindler, Engel & Rupprecht, 2012; Wright, Battista, Pate, Hierholzer, Mogelof & Howsepian, 2010).

Psychological wellbeing has also been investigated (Bristow, et al., 2008; Ervin, et al., 2015). The findings from these studies indicate that dementia caregivers exhibit greater stress, have reduced life satisfaction, higher psychological distress, poorer psychological wellbeing and are more likely to meet the criteria for depression or anxiety (Ask, et al., 2004; Bristow et al., 2008; Mausbach, et al., 2012). The relationship between physical and mental health have also been explored, indicating higher levels of CB are associated with worse physical and mental health (Andreakou, Papadopoulos, Panagiotakos and Niakas, 2016; Contador, Fernández-Calvo, Palenzuela, Miguéis & Ramos, 2012; Cucciare, et al., 2010; Hashimoto, Washio, Arai, Sasaki, Mori and Saito, 2013); some using health-related quality of life (HRQoL) as an outcome measure (Andreakou, et al., 2016).

Variables, indicated by the research, that potentially act as protective factors may include the use of formal community services. Some studies have reported that frequent attendance and regular use of Day Centres were beneficial, with caregivers reporting less CB and depression symptoms (Liu, Kim, Almeida & Zarit, 2015; Sussman & Regehr, 2009). Other findings indicated that caregivers found it beneficial to have someone to talk to, in order to understand dementia and their CR more, as well as support in developing coping strategies (Quinn, et al., 2008).

Having assistance with the caring responsibilities, for example, support from several family members to 'share care' has been associated with lower levels of CB and depression, alongside problem-focused coping, more so than emotion-focused coping strategies (Ondee, Panitrat, Pongthavornkamol, Senanarong, Harvath & Nittayasudhi, 2013). Positive subjective appraisals of providing care had also been shown to improve psychological outcomes (Weisman de Mamani, Weintraub, Maura, Martinez de Andino & Brown, 2018). This suggests that targeting subjective interpretations of the burdens associated with caregiving could help alleviate the overall mental health toll that caregivers experience.

Overall, a large number of studies examined different elements of CB in order to gain a better understanding of caregiver's experiences and responses when providing care to a PwD. Most showed that caregivers varied in their responses, indicating that caregivers' needs are multidimensional (Bristow, et al., 2008; Gouin, Glaser, Malarkey, Beversdorf and Kiecolt-Glaser, 2012; Liu, et al., 2015; Zarit, Femia, Kim and Whitlatch, 2010), which may suggest that their response to risks and thus, higher levels of stress, are individual. The majority, therefore, proposed that interventions should, therefore, be tailored to the individual, to avoid a 'one-size-fits-all' approach (Ducharme, et al., 2014). It is likely that caregivers will perceive some services as irrelevant and either reject them or accept them reluctantly, which would diminish their potential gain (Ducharme, et al., 2014).

2.3.2. Appraisal of the caregiving experience

Despite adverse and challenging circumstances, caregivers are able to show resistance to negative outcomes and display positive protective abilities, such as psychological resilience (Donnellan, et al., 2015; Joling, et al., 2016; Sánchez-Izquierdo, Prieto-Ursúa & Caperos, 2015). The focus on positive appraisals of the caregiving experience has been slowly developing and has been increasingly explored in the literature (Snyder, et al., 2015). Whereby, less emphasis is being placed on the negative aspects of caregiving, which has been the dominant focus of the research literature since the 1980s (Dickinson et al., 2017; Kršiková & Zleníková, 2018).

2.3.2.1. Positive aspects in caregiving

Nine articles explored the positive aspects of caregiving, indicating that caregivers are able to find rewarding aspects of providing care despite the emotional strain of carrying out this role (Sánchez-Izquierdo, et al., 2015; Trujillo, et al., 2016). Furthermore, it is suggested that the stress of caregiving provides an opportunity for personal development (Cheng, Mak, Fung, Kwok, Lee & Lam, 2017). The majority explored related concepts, such as finding meaning, personal growth, resourcefulness and satisfaction with the caring role, and how this relates to CB.

The findings indicate that different factors affect caregiver's ability to reflect on the positive aspects of caregiving. Factors such as, social resourcefulness, seeking help from family, friends or professionals, (Bekhet, 2015; Trujillo, et al. 2016), and reframing their experiences (Cheng, et al., 2017) were associated with positive outcomes. Some aspects of the caregiving role, however, appeared to affect the extent of gains and role satisfaction reported by caregivers, these included: an increase in caregiving tasks, i.e. greater dependency from the CR on the caregiver (Holst & Edberg, 2011; Leipold, Schacke & Zank, 2008; McLennon, Habermann & Rice, 2011; Sánchez-Izquierdo, et al., 2015); caregivers physical health (Holst & Edberg, 2011; McLennon, et al., 2011; Sánchez-Izquierdo, et al., 2015); behaviours and cognitive functioning of the CR (Holst & Edberg, 2011); cultural and ethnic factors (Bekhet, 2015; Cho, Ory & Stevens, 2016); level of education (Cho, et al, 2016); decreased opportunities for leisure activities (Sánchez-Izquierdo, et al., 2015); and mental health status (Välimäki, Vehviläinen-Julkunen, Pietilä & Pirttilä, 2009).

Overall, the studies indicate that the ability to adapt and develop skills that support caregivers to manage stressful situations will allow opportunities for skill development, being open-minded to new experiences, increase self-knowledge and develop insight (Bekhet, 2015; Leipold, et al., 2008; Välimäki, et al., 2009). It has also been proposed as a mechanism that allows caregivers to manage adverse circumstances and caregiving stressors more successfully, which enables them to reduce burden (McLennon, et al., 2011). The majority of these studies advocate for interventions that reframe the caregiving situation in a positive way (Bekhet, 2015; Sánchez-Izquierdo, et al., 2015), which could be used to enhance existing support interventions (Cheng, et al., 2017).

2.3.2.2. Psychological resilience

Six studies examined the concept of psychological resilience as a protective factor against negative outcomes, such as poor physical and mental health status, (Gulin, et al., 2018), CB and ineffective coping skills (Senturk, Akyol & Kucukguclu, 2018).

The main findings of these articles indicate that resilient caregivers stay positive (optimism), enjoy their role (satisfaction), express their concerns, adopt positive coping skills (Senturk, et al., 2018), have good psychological wellbeing (Joling, et al., 2016) and have access and use available support services (Donnellan, et al., 2015). Social participation, shared experiences with other caregivers and formal support also appear to facilitate psychological resilience (Donnellan, et al., 2015; Senturk, et al., 2018). Thereby, enabling the development of effective coping skills (Senturk, et al., 2018) and supporting the adaptation process (Deist & Greeff, 2015). Individuals higher in psychological resilience were found to be more likely to provide good quality care to their CR, as well as being respectful of the CR's wishes and level of autonomy (Gulin, et al., 2018). Living apart, men and less reported incidences of behaviour or mood problems in CR were also associated with higher psychological resilience (Joling, et al., 2016).

Overall, most studies recognised psychological resilience as a multidimensional construct, that involved a dynamic process that was not static (Donnellan et al., 2015; Gulin et al., 2018; Joling et al., 2016; O'Rourke et al., 2010). This suggests that psychological resilience has the potential to be nurtured and may indicate potential areas to focus interventions, in order to support caregivers (O'Rourke et al., 2010).

The six studies included in this review focussed on psychological resilience, the majority from an individual perspective and one study from a family perspective (Deist & Greeff, 2015). Different outcomes were used to measure psychological resilience; however, all studies used a similar definition that, psychological resilience is a process of adaptation in response to adversity or stressful events that allow an effective response in order to help maintain stable functioning. As research in the area of dementia caregivers and psychological resilience is still limited, the concept of psychological resilience is emerging and being developed as a viable protective factor that requires further examination.

2.3.3. Engagement with services

Several studies examined caregiver's engagement with formal support services. The majority seeking to investigate predictive factors for support service use through the type of services utilised, namely day centres or residential respite services. One study provided an evaluation of support services from a caregiver's perspective.

2.3.3.1. Evaluation of services

Of those studies included in this review, only one study evaluated family caregiver's preferences for community-based services. Putnam, Pickard, Rodriguez and Shear (2010) used focus groups to explore caregiver's perceptions of using support. Their findings indicate that caregivers prefer more choice and wider options to arrange formal support provision that are tailored to the individual needs of the CR and match their own capacity to provide care. The study was conducted in the USA, due to variance of social funded support and services offered, these findings may be limited in their generalisability. An interesting finding of note is, that caregivers stated that they would like more support, not in order to relinquish their duties, but in order to maintain their role.

2.3.3.2. Type of services utilised

Four studies sought to examine predictive factors of support service use and non-use for dementia caregivers and their CR's. Services included use of residential respite, Day Centres, in-home help and support from professionals, for example, GPs or nurses. A number of factors are indicated for service use and non-use, including caregiver and CR characteristics, psychological and socio-demographic factors.

The majority of findings suggest that use of services, especially respite and day centres, were related to increased dependence of the CR, health problems (Brandão, Ribeiro & Martín, 2016) and receiving support from family and friends (Maseda, González-Abraldes, de Labra, Marey-López, Sánchez & Millán-Calenti, 2015). Roelands, van Oost and Depoorter (2008) investigated a broad range of community-based support services, their main results indicating that co-habitation, type of coping strategies and behaviours of the CR were important indicators of service use.

Factors that influenced non-use of services included, a strong sense of family and cultural factors, where family felt obligated and were expected to care for their loved one (Brandão, et al., 2016), CRs reluctance to attend services, CRs that required less assistance and were more cognitively intact, and caregivers concerned that service use would result in negative outcomes for their CR (Phillipson, Magee & Jones, 2013). Being unaware of available services, however, was found to be the main reason for non-service use by Brandão, et al. (2016). Their findings also suggest that caregivers that were already familiar with services were more likely to use other available services.

Findings suggest that respite was used as a 'last resort' or viewed as a 'stepping stone' to a more permanent placement (Phillipson, et al., 2013). This also indicates that caregivers delayed service use, until deemed necessary or as part of the deteriorating disease pathway (Phillipson, et al., 2013). Suggesting that caregivers use services, such as respite, as their situation deteriorates, thus, indicating that services are unplanned, a reactive measure, rather than as a preventative measure against CB.

Overall, all studies recommend increasing the awareness of available support services and promoting positive outcomes for the CR and caregiver alike to increase engagement with services. One possibility that was suggested, was through known and trusted support systems already in use (Brandão, et al., 2016). It was also advocated that the transitional nature of dementia is acknowledged and that support needs may change as the disease progresses (Phillipson, et al., 2013), thereby, proposing that support services on offer are reviewed at different stages of the disease and altered to meet current and changing needs.

2.3.4. Other factors

The experiences of caregivers of PwD is multifaceted and encompass a range and multitude of variables. Other factors that influence the caring experience that has also been explored within the literature, not comprised within the scope of this review, can be found in Appendix C, as well as a synopsis of determinants of CB (Appendix D). The extent to which these factors influence the level of psychological distress and CB experienced by dementia caregivers are wide-ranging and not consistently reported in the literature (Stinson, et al., 2014). This may be explained by the methodological differences in approaches, definitions, inclusion and exclusion criteria, and taking into account the differing support offered within different countries (Baker & Robertson, 2008; Stinson et al., 2014). The similarities in findings, however, is greater than the difference and the burden of caregiving is determined by more than one measurable variable (Gallagher-Thompson & Powers, 1997).

2.3.5. Summary

This review summarised and briefly evaluated sixty studies. The scope was intentionally broad to capture a range of aspects spanning positive and negative factors of providing care, support service use, characteristics of caregivers and their CR's, as well as finding meaning and the role of psychological resilience. Hierarchical ordering of study designs was not used, due to the wide-ranging scope of the studies examined (Kmet, et al., 2004).

As suggested by the literature, the spousal relationship has been deemed to be distinct from others (O'Rourke, et al., 2010), although risk factors have been identified for all caregivers who provide care to a PwD, albeit to a greater or lesser extent (Lee, et al., 2017). These risk factors have been shown to have a bearing on the emotional wellbeing of caregivers, however, they may also determine their ability to be flexible and adapt in providing care (Senturk, et al., 2018). In addition, physical health may determine how much care they can safely provide (Holst & Edberg, 2011). The increasing dependence that the CR has on their caregiver has been shown to be related to the risk of developing depression; this is exacerbated by the level of deterioration of the dementia syndrome (Holst & Edberg, 2011; Meyer, et al., 2016; Välimäki, et al., 2009). Providing an increasing amount and level of care over an uncertain period of time, can increase the risk of social isolation and decrease the level of social participation (Nay, et al., 2015).

This review explored the literature on the experiences of dementia caregivers and the impact of providing care on their psychological wellbeing, examining positive aspects, psychological resilience and use of support services. Furthermore, the need for a clearer understanding of how caregivers continue within their role, despite negative outcomes and the influence of positive outcomes is highlighted. Moreover, it is indicated that the transitional and dynamic nature of the dementia syndrome needs to be taken into account, especially in regard to providing support services that may need to alter, increase or adapt according to the varied needs of the CR and their caregiver.

2.4. Current study and rationale

An important aspect of the research on dementia caregivers, as indicated by the findings of this review, identifies the potential unmet needs of family care providers, and the importance of supporting these individuals to maintain their psychological wellbeing (Droës, et al., 2004). Meeting the needs of the caregiver (Innes, Blackstock, Mason, Smith & Cox, 2005), will in turn benefit the CR, "treating the carer improves the quality of life of the sufferer" (Manthorpe et al., 2003, p. 479). It is, therefore, important to incorporate caregivers into a framework of dementia care, that recognises the impact of providing care, which supports their own needs, as well as that of the PwD (Dickinson et al., 2017; Nolan & Keady, 2001).

The negative aspects of providing care have been dominant within the research literature (Dickinson et al., 2017; Keeling et al., 2008; Sanders et al., 2008; Zarit & Edwards, 2008), however, none appeared to be attached to a positive psychological concept (Donnellan et al., 2015; Snyder et al., 2015), which might enable a carer to better cope with the burden of care and maintaining their role. A predominant approach within the literature, is Lazarus and Folkman's 'transactional model of stress and coping' (1984) which can be argued to lack, within its concept, a caregiver's ability to endure longer than others and cope with the deterioration of a loved one. This attribute could be considered psychological resilience.

Understanding the factors that contribute to a resilient outlook, may enable a caregiver to increase their capacity to cope and reduce their likelihood of developing negative and risky health behaviours, for example, excessive drinking, smoking and altered sleep patterns (Aboulafia-Brakha, Suchecki, Gouveia-Paulino, Nitrini & Ptak, 2014; Cherry et al., 2013), which in turn would benefit the PwD. Thus, introducing the concept of psychological resilience as a mechanism to explore the experiences of dementia caregivers may provide professionals and support services with a better understanding of the barriers and protective strategies that allow for success and perceived failure on the part of the caregiver (Stine-Morrow & Chui, 2012).

2.4.1. Psychological resilience

The introduction of psychological resilience as an alternative perspective attempts to provide a more holistic and integrative biopsychosocial model of understanding, rather than on a fixed mono-causal model for stress and coping (Davydov, Stewart, Ritchie & Chaudieu, 2010). The concept of psychological resilience may be a useful predictor of CB and mental health states and could be used to identify vulnerable caregivers (Cherry et al., 2013; Patterson et al., 2010). Individuals higher in psychological resilience are more likely to use effective coping strategies, adapt and recover quicker in adverse circumstances, and are more likely to perceive opportunities for personal growth (Fernández-Lansac & Crespo, 2011; Zautra, 2009).

To date, there has been limited research exploring the role of psychological resilience as it mitigates the negative impact of providing care for PwD. More emphasis is now being placed on the prevention of psychological distress (for example, depression) and the promotion of emotional and social wellbeing for dementia caregivers (Orgeta, Lo Sterzo & Orrell, 2013).

In order to achieve this, further understanding of the important coping resources or factors that enhance psychological resilience and wellbeing among dementia caregivers will be essential. This understanding can serve as a basis for the design of interventions that target the emotional, social, and mental wellbeing of dementia caregivers who may potentially be at risk (Cherry et al., 2013).

2.4.1.1. Defining psychological resilience

Psychological resilience has historically been entrenched in child development and adopted to describe how individuals 'bounce back' when challenged (Howe, Smajdor & Stöckl, 2012; Smith & Hollinger-Smith, 2015). Different fields have translated, defined and used the concept of psychological resilience (Wilks & Croom, 2008). Most definitions acknowledge two points; firstly, that it is an interactive dynamic process and, secondly, psychological resilience is time and content specific (Herrman, Stewart, Diaz-Granados, Berger, Jackson & Yuen, 2011). Psychological resilience has been defined as:

> "the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary" (Windle, 2011, p. 163).

For the purposes of this study, this definition offered by Windle (2011) is used, as it reflects the "dynamic or interactive nature of resilience throughout the lifespan" (Herrman, et al., 2011, p. 263). Furthermore, the Psychological Resilience Measure (PRM) was used in this study to measure psychological resilience in caregivers (Windle, Markland & Woods, 2008).

2.4.2. Psychological wellbeing

Promoting and maintaining psychological wellbeing has been an important focus over the past decade (Morrison, 2008; Sin & Lyubomirsky, 2009), especially in regard to combatting

CB in dementia caregivers (Orgeta, et al., 2013). It can be viewed as "not only the absence of mental disorder but also the presence of positive psychological resources" (Sin & Lyubomirsky, 2009, p. 468), and thus, as a general indicator of successful adaptation (Smith, Borchelt, Maier & Jopp, 2002).

The concept of burden has been used previously in the research literature, as a measure for caregiver outcomes, to evaluate the impact of providing care to a PwD (Argimon, Limon, Vila & Cabezas, 2004; Välimäki, et al., 2009). As a shift towards a more 'positive psychology approach' occurs (Snyder, et al., 2015), the use of wellbeing as an outcome measure reflects this move, with a greater focus on positive aspects of caregiving (Sánchez-Izquierdo, et al., 2015). Negative and positive elements of caregiving can co-exist, emphasising that wellbeing can be improved despite CB (Argimon, et al., 2004; Crellin, Orrell, McDermott & Charlesworth, 2014).

Current approaches in the literature incorporate both physical and mental health aspects to evaluate and measure psychological wellbeing (Crellin, et al., 2014; Orgeta, et al., 2013), which has been suggested as a central component of HRQoL (Argimon, et al., 2004). HRQoL is considered a multidimensional perspective of an individual's subjective view of their physical, psychological and social functioning on their general wellbeing (Andreakou, et al., 2016; Välimäki, et al., 2009). Thus, for the purposes of this study, psychological wellbeing was conceptualised as HRQoL and was measured using the Medical Outcomes Study 36-item Short Form Health Survey (SF-36v2; Ware, 2000, 2007).

2.4.3. Aims

The overall aim of this research study, is firstly, to highlight lived experiences of family caregivers of a PwD; secondly, to explore the role of psychological resilience in their ability to adapt and maintain their role as a care provider; and finally, to identify and examine their perspectives of current support services in meeting their needs. It is hoped that this will allow a greater understanding of the individual differences of dementia caregivers, and therefore, provide opportunities to inform future interventions and appropriate support and service development initiatives. Furthermore, it may allow less resilient caregivers to be targeted who may be at higher risk of psychological distress, which in turn will impact on their ability to maintain and manage their caregiving role.

2.4.4. Methodological approach

This study will investigate the experiences of dementia caregivers by adopting a mixed methodological approach with two phases, where Phase I directs Phase II. Creswell and colleagues suggest that,

> "mixed method research … is more than simply collecting qualitative data from interviews or collecting multiple forms of qualitative evidence (e.g. observations and interviews) or multiple types of quantitative evidence (e.g. surveys and diagnostic tests). It involves the intentional collection of *both* quantitative and qualitative data and the combination of the strengths of each to answer research questions" (Creswell, Klassen, Plano Clark & Smith, 2011, p. 5).

In this mixed methodology design, the quantitative data will be prioritised, being collected first and analysed, followed by the qualitative phase of this study. This is to compliment and expand the potential findings derived from the quantitative results (Hanson, Creswell, Plano Clark, Petska & Creswell, 2005), therefore, an explanatory sequential design is proposed, QUAN → qual (Creswell et al., 2011; Hanson, et al., 2005).

2.4.4.1. Hypotheses and research questions

The following research questions (RQ) were proposed to inform the whole study; further hypotheses and research questions were formulated to inform Phase I and II, respectively (please see Section 3.2.1. Hypotheses and Section 4.2.1. Research questions for further details).

RQ1: To what extent does providing care impact on caregiver's ability to sustain and maintain their role?

RQ2: How does psychological resilience and wellbeing factors influence caregiver's awareness, access and use of available support services in order to provide care?

RQ3: To what extent does awareness, access and use of available support services effect caregiver's ability to provide care?

2.4.4.2. Phase I

As a clarification, Phase I of this study is a quantitative approach using a postal survey strategy, which will address the sub-hypotheses. This format has been widely used as a flexible and valuable method to gather research information quickly from large, geographically dispersed populations, and tends to have higher response rates than internet surveys (Edwards, et al., 2002; Shaughnessy, Zechmeister & Zechmeister, 2000; Vaux & Briggs, 2006). Access to other media and technologies, such as the internet and e-mail, were avoided, as many participants may not have access to these facilities (Coolican, 2004).

It is recognised within the research literature, however, that postal surveys have a low response rate, on average around 30%, which may reduce the effective sample size (Edwards et al., 2002; Shaughnessy, et al., 2000). Despite some of the disadvantages of a postal survey, this remains a widely used format to collect data (Edwards et al., 2002); and has been routinely used in dementia research (Georges, et al., 2008).

2.4.4.3. Phase II

The qualitative phase of this study, Phase II, was directed and informed from the findings in Phase I (Creswell et al., 2011), and will address sub-research questions directly. From the postal survey, several factors were identified that necessitated further expansion, and thus, informed the questions in the semi-structured interview. The advantage of using a qualitative interview, is that it generates extensive and rich data on the subject under investigation (Howitt, 2013), and is best suited to exploring, "understandings, perceptions and constructions of things that participants have some kind of personal stake in" (Braun & Clarke, 2013, p. 81). In addition, the outcomes from Phase I were used to identify suitable participants based on set criteria, which was then used to recruit to the interview process.

Few research studies on dementia caregivers have incorporated a postal survey, followed by an interview process, using a UK-based population sample. Where studies have incorporated a combination, the majority have used a concurrent design, in which data is collected and analysed at the same time (Hanson, et al., 2005).

2.4.5. Ontological and epistemological stance

Bury and Strauss observe,

> "at its core, counselling psychology privileges respect for the personal, subjective experience of the client over and above notions of diagnosis, assessment and treatment, as well as the pursuit of innovative, phenomenological methods for understanding human experience" (2006, p. 113).

Thus, the philosophical foundation of counselling psychology is firmly rooted within phenomenological and humanistic concerns, as well as that of reflexivity (Bury & Strauss, 2006), in which the search for understanding and meaning is central, and also focusses on the engagement with subjective experience, values and beliefs (Strawbridge & Woolfe, 2010).

Within the research process, it is suggested that an interrelationship exists between the researcher and the theoretical stance they adopt, their methodology and methods used, as well as their epistemological view (Crotty, 1998). Whilst ontology is concerned with “what is” (Gray, 2014, p. 19) and the nature of reality (Hanson et al., 2005), epistemology is about “how we know what we know” (Crotty, 1998, p. 8).

In the case of the present study, there is a philosophical dilemma. It could be claimed, that Counselling Psychology takes on a socially constructed worldview, underpinned by a relativism ontology (Braun & Clarke, 2013; Gray, 2014), best suited for qualitative procedures. The use of a mixed method design could be argued to compete against this philosophical paradigm. The incorporation of post-positivist research, within a realist ontology, emphasises a quantitative approach (Gray, 2014).

The perspective is emerging that the use of both quantitative and qualitative methods could be complimentary, thereby, placing greater emphasis on the research question. This outlook,

> “maintains that mixed methods research may be viewed strictly as a ‘method’, thus, allowing the researcher to use any number of philosophical foundations for its justification and use. The best paradigm is determined by the researcher and the research problem – not by the method” (Hanson et al., 2005, p. 226).

This study attempts to understand the lived experiences of dementia caregivers, using methods that gain their perspective, where the phenomenological philosophical positions of Counselling Psychology are not undermined, while using the mixed method within an empirical approach to clarify and enhance the understanding of this lived experience.

2.5. The role of Counselling Psychology

Kitwood (1995) advocates that effective caregiving requires a competency in the standard tasks of the role, benefitting from: “a well-developed experiential self. This involves being familiar with the world of feeling and emotion; being willing to bear the burden that arises from attachment; being comfortable with an intimacy that needs no words; and being capable of play” (Baldwin & Capstick, 2007, p. 242). It is suggested that, this could be fostered within family caregivers if they are well supported, even whilst they endure the burden and stress of caregiving (Baldwin & Capstick, 2007).

Counselling Psychology provides “conditions for people to fulfil their needs for life meaning, security, love and respect, self-esteem, decisive action and self-actualizing growth; […] it also means providing resources and skills that enable people to help themselves” (Brammer, Abrego & Shostrom, 1993, p. 1). Theoretical and evidence-based approaches to psychological interventions are key concepts within Counselling Psychology practice. This psychological profession is well placed to support dementia caregivers to move towards ‘acceptance’ of behaviours and the explicit grieving process needed to cope with the emotional situation and physical strain, brought about by the dementia condition (Miesen, 1997).

2.6. Conclusion

The “role of the caregiver is not a new phenomenon” (International Council of Nurses [ICN], 2009, p. 143). It remains an important element in regard to an aging population, and the provision of care may encompass many different elements and vary in needs, resources, strengths, limitations and services (ICN, 2009). The process of giving care is a complex and multifaceted process (Zarit & Edwards, 2008). It is, therefore, unsurprising that the physical, psychosocial and economic demands placed on dementia caregivers have led to negative health outcomes, increasing their risk for physical and mental illness (Stajduhar & Cohen, 2009).

Over three decades, a vast amount of research has been produced with an aim to identify, explain and understand the caregiving experience within a context of dementia care (Kršiková & Zleníková, 2018; Sanders et al., 2008). More recently, there has been a shift away from a 'deficits model', with the aim of developing interventions based on a concept of building psychological resilience, which may encourage a move towards a more positive psychology agenda (Bayne, 2012; Burns, et al., 2011; Howe et al., 2012). One which, Counselling Psychology is potentially well-placed and poised to lead on.

In summary, it is hoped that this research thesis will represent the views and experiences of a group of dementia caregivers, which may offer an insight to all dementia caregivers. In trying to capture a small increment of their individual lived experiences, its aim is to encourage clinical practitioners and service providers to 'think outside the box' and enhance their understanding of the caregiving role and how improving this might lead to the benefit of the PwD.

Chapter 3

Phase I: Quantitative approach

3.1. Introduction

The following provides a brief introduction to Chapter 3. For a more in-depth review of the literature, please see Chapter 2, Systematic review.

It is acknowledged that providing care to a PwD is a demanding and fluctuating process (Ingebretsen & Solem, 1997) and that caregivers are, particularly, at an increased risk of; developing high levels of stress, poor mental and physical health, and a diminished quality of life (NICE & SCIE, 2007; Ott, Kelber & Blaylock, 2010; WHO, 2012). Previous research on dementia caregivers has indicated that it is, therefore, important to explore the risk and protective factors related to the psychological wellbeing of these individuals; as this will likely influence service provision and intervention (Bekhet, 2015). A mixed methodological approach was utilised in two phases to investigate the experiences of dementia caregivers.

3.2. Phase I

In Phase I, a postal survey was used to gather information from known dementia caregivers in the Telford and Wrekin Borough, Shropshire (The Borough). Quantitative data has the advantage of exploring the relationship among variables, producing information that can be generalisable to other situations or contexts and yield replicable results (Creswell, et al., 2011; Gray, 2014).

The results from the quantitative approach will be utilised to recruit participants and inform the basis for the semi-structured interviews which makes up Phase II of this study. This second phase will be discussed in Chapter 4, Phase II: Qualitative approach.

The rest of this chapter sets out the method and results for Phase I.

3.2.1. Hypotheses

The following sub-hypotheses (H) were proposed to inform the first phase of this study:

H1: The provision of care will have a negative impact on caregivers' ability to sustain and maintain their role.

H2: Caregivers with higher psychological resilience and wellbeing (physical and mental health) outcomes will be more likely to be aware of, access and use available support services.

H3: Being aware of, accessing and using available support services would have a positive impact on caregiver's ability to provide care.

3.3. Method

3.3.1. Design

A cross-sectional survey design was used to explore the experiences of caregivers of a PwD and the impact on the caregiver's psychological wellbeing (HRQoL), the association between psychological resilience on providing care, and caregiver's awareness and utilisation of support was also examined.

3.3.2. Participants and recruitment

The target population was family members who support a PwD in the community, who live in The Borough. A purposive sampling method was used to recruit participants, these were all caregivers linked with the Admiral Nurse's Service in the area. The final sample size consisted of 45 participants.

3.3.3. Measures

Participants completed a paper-based survey comprised of three sections (Appendix E).

3.3.3.1. Section 1: Socio-demographic information

Section one contained socio-demographic questions, which were developed based upon research literature on dementia caregivers and known predictors of CB. For justification for the inclusion of these variables, see Appendix F. These were grouped under: caregiver characteristics; CR characteristics; providing care; access and awareness of support services; and support services used. For a full breakdown, see Appendix G.

3.3.3.2. Section 2: Psychological wellbeing

The original proposed questionnaire, General Health Questionnaire-28 (GHQ-28; Goldberg & Williams, 1988), was rejected by the University of Wolverhampton Ethics Panel (see Appendix H for additional information) and the SF-36v2 (Ware, 2000, 2007) was suggested as an alternative.

The SF-36v2 is a 36-item measure that produces a profile of eight health domain scales (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health) and two health component summary measures. These were the Physical Component Summary (PCS) and the Mental Component Summary (MCS; Ware 2007; Ware & Gandek, 1998). Measures of internal consistency showed $\alpha = 0.94$ and $\alpha = 0.89$, respectively (Gandek, Sinclair, Kosinski & Ware, 2004). The SF-36v2 utilises norm-based scoring, thus, general population norms, including age and gender, are built into the scoring algorithm ($M = 50$, $SD = 10$; Ware, 2007). For all health domain scales and component summary measures, therefore, scores below 50 can be interpreted as being below the average range of the general population (Ware, 2007).

It has also been found to be reliable and valid for the use with older adults and other demographic groups (Jones, Jones & Miller, 2004; Ware, 2007). The SF-36v2 (Ware, 2000,

2007) was, therefore, used in this study to measure psychological wellbeing, conceptualised as self-reported HRQoL (Lins & Carvalho, 2016; Moniz-Cook, et al., 2008).

A license agreement and permission to use the SF-36v2 was granted from QualityMetric Incorporated (Appendix H).

3.3.3.3. Section 3: Psychological resilience

Following a discussion with the academic supervisors of this study, it was advised that the Psychological Resilience Measure, α = 0.83 (PRM; Windle, et al., 2008) was the 'best fit' for the sample population. This decision was based upon the evidence contained in the systematic review of psychological resilience measurement scales by Windle, Bennett and Noyes (2011) and consideration of the fourteen measures in the review.

The purpose of the PRM is the assessment of psychological resilience (self-esteem, personal competence and interpersonal control) that acts as a protective factor against risk and adversities; as well as a moderating effect between ill-health and wellbeing (Windle et al., 2011). It is a 19-item questionnaire, comprising of three sub-scales, assessing self-esteem, interpersonal control and personal competence. This measure was developed through secondary data analysis using empirically validated measures (Windle, et al., 2011).

The self-esteem component comprises of the 10-item Rosenberg Self Esteem Scale (Rosenberg, 1965), α = 0.84, and uses a five-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The interpersonal control component consists of 5-items from the Spheres of Control scales (Paulus & Christie, 1981), and questions are rated on a seven-point Likert scale that ranges from 'strongly disagree' to 'strongly agree', α = 0.71. The personal competence scale comprises of six-items from the Resilience Scale (Wagnild & Young, 1993), α = 0.70, and is scored on a seven-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. Overall, high scores indicate higher levels of psychological resilience (Windle, Woods & Markland, 2010).

3.3.4. Ethical Considerations

Ethical approval for this study was granted by the Faculty of Education, Health and Wellbeing Ethics Panel, The University of Wolverhampton (UoW; Appendix I), Telford and Wrekin Council and the Clinical Governance Committee (Telford and Wrekin; Appendix J).

3.3.5. Procedure

In order to promote a favourable response rate, the appearance of the survey was made consistent and had a uniform look (King, Pealer & Bernard, 2001). It was hoped that a uniform questionnaire format and accompanying information documentation would look professional, legible and, therefore, be easier to complete (Edwards, et al., 2002; Vaux & Briggs, 2006). The questionnaire format was edited using Adobe Photoshop cs6.

Each postal survey pack included: an introductory letter from the Carer's Commissioner of Telford and Wrekin Council; a 'Keep data safe' leaflet; a participant information sheet; a consent form; a withdrawal form; a questionnaire; a self-addressed stamped envelope; and a 'useful contact' information sheet (Appendix E). The 'useful contact' sheet contained information about appropriate support agencies and how to communicate with the researcher and their institution, behind this project. The pack was distributed via the Admiral Nurse's Service in The Borough, on behalf of the researcher, to known family caregivers of PwD (in August 2015).

Each questionnaire had a unique 'survey code' (e.g. S-202); which corresponded to a unique 'participant code' (e.g. P-22). The consent and withdrawal forms were given the same 'participant code'. This enabled a particular participant to be identified, whilst maintaining anonymity and confidentiality of personal identifiable information. Participants had to be identified, either for an invitation to an interview for the second phase of this study, if they had provided consent, or in order for their data to be removed from the analysis if they wished to withdraw, at a later stage.

Two secure password protected databases were set up, on an encrypted computer. One database contained the 'participant code', which corresponded to the 'survey code'. A second database contained the 'survey code', which corresponded to the identity number used in the statistical analysis. Raw data and contact information were kept in a secure cupboard in a locked room. On completion of the study, contact information was destroyed. Raw questionnaire data will be kept for up to three years, at the UoW, in secure premises, in line with the University's data policy (UoW, 2015).

3.3.6. Statistical Analysis

Data was analysed using SPSS (version 20). The eight domain scales and two health component summary scores of the SF-36v2 were calculated using the QualityMetric Incorporated Health Outcomes Scoring Software 4.5 (QualityMetric Incorporated, 2011); which was supplied as part of the licence agreement. As part of this package, a first stage positive depression screening was also calculated.

Descriptive statistics, mean, standard deviations and percentages, were calculated for all variables. The open-ended questions were evaluated using content analysis (Coolican, 2014; Howitt, 2013).

The aggregate function in SPSS was used for all questions that produced multiple responses, where participants indicated more than one response per survey question. Aggregated data combines multiple observations into a single line of data (Atkins, 2012). A coding framework was developed, where possible, for each question. This information was used to recode the multiple response questions into a summary form, for use in statistical analysis.

Analysis of the research data were addressed through the use of frequency and contingency table analysis, chi-square test of independence, and multinomial logistic regression analysis (MLR). MLR analysis were performed, as it is well suited for modelling the relationship between an outcome variable with more than two categories, with one or more categorial or continuous predictors (Field, 2011). Eight MLRs were performed in total. The first five regressions related to the factors for providing care and the next three related to factors for engagement with support services. Significant main effects for the MLRs are reported within the text, for a full breakdown of MLR results, please see Appendix K.

3.4. Results

3.4.1. Response rates

A total of 157 questionnaires were posted. Fifty-five questionnaires were returned in total, a 35% return rate. Three uncompleted questionnaires were returned where the participants opted out, as their CR had either passed away or they felt it was inappropriate to complete, for example, due to their CR now being in a nursing home. An additional questionnaire was excluded from the data analysis, due to the CR having moved into a nursing home, more than 6 months in length; it was felt that their data would not be reflective of caregivers currently providing care in the community.

3.4.2. Screening the data

3.4.2.1. Missing data

In analysing the data, 6 completed questionnaires had missing data. This may possibly be due to participants missing several pages in error when filling out the survey. Missing data from the SF-36v2 could not be analysed using the QualityMetric Outcomes Scoring Software 4.5, therefore, these 6 incomplete questionnaires were excluded. Thus, 45 complete questionnaires were used in the final data analysis; a 28.7% response rate.

Participants may have chosen not to answer questions that they felt were of a personal or sensitive nature. For example, 7 participants chose not to disclose their income (15.6%).

3.4.2.2. Power analysis

A post-hoc power analysis was performed using G*Power 3.1 (Faul, Erdfelder, Buchner & Lang, 2009). To detect a small to medium effect size (0.09), the study sample of 45 participants obtained a statistical power at a 0.33 level. This indicates a 33% chance of detecting a genuine effect (Field, 2011).

3.4.2.3. Outliers

The data scores from the SF-36v2 and the PRM were examined for outliers, which was classified as exceeding a z-score above 3.29 (Field, 2011). None were identified above this level.

3.4.2.4. Tests of normality

Scores from the SF-36v2 and the PRM were screened to test for parametric assumptions. Results of skewness and kurtosis were within normal assumptions. Visual inspection of histograms, normal Q-Q plots and box plots showed SF-36v2 and PRM scores were approximately normally distributed. The parametric assumptions were met, however, data gathered from section one of the survey can be classed as categorical or ordinal data. Non-parametric tests were performed with the data, due to variables being predominantly categorical in nature.

3.4.3. Preliminary analyses

3.4.3.1. Socio-demographic information

3.4.3.1.1. Caregiver and care recipient characteristics

Descriptive statistics for caregiver and CR characteristics are presented in Table 4, and a full breakdown can be found in Appendix L. Caregivers were aged between 47 and 89 years (*M* = 67.11, *SD* = 10.90), more than half were female (58%) and a spouse or co-habiting partner (69%) to the CR. Seventy-eight percent of caregivers (*n*=36) reported a physical health condition, of which the majority were ‘musculoskeletal and nervous system’ (40%).

Care recipients were aged between 52 and 94 (*M* = 79.07, *SD* = 8.40) of which, 60% were female.

Table 4

Caregiver and care recipient characteristics

Characteristics	Caregiver [*n*(%)]	Care Recipient [*n*(%)]
Age		
45 – 54 years	7 (15.9)	1 (2.2)
55-64 years	9 (20.5)	1 (2.2)
65-74 years	15 (34)	11 (24.4)
75-84 years	12 (27.3)	18 (40)
85< years	1 (2.3)	14 (31.2)
Type of Dementia		
Alzheimer's Disease	-	21 (55.3)
Vascular Dementia	-	8 (21.1)
Front-temporal Dementia	-	1 (2.6)
Lewy Body Dementia	-	2 (5.3)
Mixed	-	4 (10.5)
Other	-	1 (2.6)
Unknown	-	1 (2.6)
Stage of Dementia		
Early stage	-	6 (13.3)
Middle stage	-	23 (51.1)
Late stage	-	7 (15.6)
Final stage	-	3 (6.7)
Unknown	-	6 (13.3)
Relationship to Care Recipient		
Husband	15 (33.3)	
Wife	14 (31.1)	
Daughter	11 (24.4)	
Son	2 (4.4)	
Partner	2 (4.4)	
Other e.g. Niece	1 (2.2)	
Employment Status		
Retired	30 (66.7)	
Part-time Work	5 (11.1)	
Full-time Work	5 (11.1)	
Unemployed	2 (4.4)	
Other	3 (6.7)	
Income		
Under £16,000	14 (36.8)	
£16,000 - £20,000	13 (34.2)	
£21,000 - £25,000	3 (7.9)	
£26,000 - £30,000	4 (10.5)	
£36,000 - £40,000	2 (5.3)	
£41,000 - £55,000	2 (5.3)	
Physical health problems		
Musculoskeletal & nervous system	20 (40)	
None	11 (22)	
Cardiovascular	4 (8)	
Other	4 (8)	
Mental health	3 (6)	
Cancer	3 (6)	
Respiratory	2 (4)	
Metabolic & endocrine	1 (2)	
Oral & gastrointestinal	1 (2)	
Ear	1 (2)	

3.4.3.1.2. Providing care

The factors related to providing care are displayed in Table 5.

Table 5

Factors related to providing care

Factors		*n* (%)
Care Length		
	1-6 Months	1 (2.3)
	6 Months – 1 Year	3 (6.8)
	1-2 Years	8 (18.2)
	3-4 Years	12 (27.3)
	5 Years or more	20 (45.5)
Share Care		
	Lone Caregiver	25 (45.5)
	Share care with paid help	17 (30.9)
	Share care with family/friends	13 (23.6)
Type of Care		
	Domestic Care	45 (25.3)
	Companionship	42 (23.6)
	Medical or Mental Health Support	39 (21.9)
	Personal Care	32 (18)
	Physical Support	20 (11.2)
Leave frequency		
	At least once a day	27 (60)
	At least once a week	1 (2.2)
	Once or twice a month	15 (33.3)
	Never leave the house	2 (4.4)
Stand-In Care		
	Family	16 (30.8)
	No-one	13 (25)
	Paid Companion	12 (23.1)
	Friends	7 (13.5)
	Other	2 (3.8)
	Neighbours	1 (1.9)
	Organisation	1 (1.9)

Table 6

Factors related to access and awareness of support services

Factors		*n* (%)
Funding of Paid Support		
	Both	10 (41.7)
	Professional	8 (33.3)
	Private	6 (25)
Frequency of Paid Support		
	None	22 (49)
	Every day	13 (29)
	Once a week	3 (7)
	Several times a week	6 (13)
	Once a month	1 (2)
External Support		
	Family	23 (30.7)
	Health Professionals	22 (29.3)
	Friends	10 (13.3)
	Organisation	7 (9.3)
	None	6 (8)
	Neighbours	4 (5.3)
	Other	3 (4)
How made aware of support services		
	Health professionals / GP	29 (69.0)
	Own resources	4 (9.5)
	Social Services / Council	3 (7.1)
	Other	6 (14.3)
When made aware of support services		
	At diagnosis	19 (44.2)
	6 months since diagnosis	3 (7.0)
	1 year after diagnosis	7 (16.3)
	More than 1 year after diagnosis	9 (20.9)
	Previous aware	3 (7.0)
	Other	1 (2.3)
	Unaware	1 (2.3)
Awareness of type of services available		
	Admiral Nurses Service	9 (26.5)
	Professional support / Memory service	9 (26.5)
	Carer support services	6 (17.6)
	Other	4 (11.8)
	Charitable organisations	2 (5.9)
	Paid care services	2 (5.9)
	Social Services / Council	2 (5.9)

3.4.3.1.3. Access and awareness of support services

The factors related to access and awareness of support services are displayed in Table 6. Thirty-four percent of caregivers indicated that they found it difficult to find out about support services.

3.4.3.1.4. Support services used

Table 7 displays the factors related to support services used, not used and what participants indicated that they have found useful instead. Support services for caregivers included caregiver groups, drop-in sessions and pamper sessions. Content analysis was used to identify two main themes (Coolican, 2014; Howitt, 2013), these are presented in Table 8.

Table 8

Themes identified related to support services used

Un-co-ordinated	Hidden
"There are so many, none in contact with each other, no central person in charge" (Participant 51)	*"Only got help when mum went into hospital" (Participant 16)*
"Need single point of contact, services / help not linked" (Participant 38)	*"Without input from Admiral Nurses would not know" (Participant 24)*
"Services not co-ordinated" (Participant 10)	*"I did not know who to ask for help when he was diagnosed" (Participant 44)*
"Support not in the form required" (Participant 28)	

Most participants reported that they found charitable organisations (24%) useful as an alternative support service.

Table 7

Factors related to support services used

Factors		*n* (%)
Support services used		
	Admiral Nurses Service	22 (27.8)
	Professional Support	10 (12.7)
	Memory Service	9 (11.4)
	Support for caregiver	9 (11.4)
	Charitable Organisations	7(8.9)
	Paid Care	7 (8.9)
	Carer's Contact Centre	7 (8.9)
	Social Services	5 (6.3)
	None used	2 (2.5)
	None indicated	1 (1.3)
Support services not used		
	Support for caregiver	7 (36.8)
	Unaware / Not known	6 (31.6)
	None	2 (10.5)
	Professional Support	1 (5.3)
	Memory Service	1 (5.3)
	Carer's Contact Centre	1 (5.3)
	Paid Care	1 (5.3)
What other support services have you found useful instead? (Alternative support services)		
	Charitable Organisations	9 (24.3)
	Admiral Nurses Service	6 (16.2)
	Support for caregiver	6 (16.2)
	Memory Service	3 (8.1)
	Carer's Contact Centre	3 (8.1)
	None used	3 (8.1)
	Professional Support	2 (5.4)
	Paid Care	2 (5.4)
	Family / Friends	1 (2.7)
	Self (Caregiver)	1 (2.7)
	Spiritual (Church)	1 (2.7)

3.4.3.2. Psychological resilience and wellbeing measures

Descriptive statistics for psychological resilience and wellbeing measures are presented in Table 9. Participants who scored above the average for this sample on the PRM (*M* = 79.93, *SD* = 13.76) were considered to have high psychological resilience (47%), and those who scored below the average were considered to have low psychological resilience (53%).

Table 9

Psychological resilience and wellbeing measures (n = 45)

Variables	*M*	*SD*
Physical Component Summary (PCS)	46.38	9.67
General health	45.46	10.13
Physical function	45.10	9.84
Role physical	43.07	9.9
Bodily pain	45.72	10.28
Mental Component Summary (MCS)	40.73	11.21
Vitality	44.02	9.78
Social function	40.52	10.48
Role emotional	41.08	12.08
Mental health	41.96	10.52
Psychological Resilience Measure (PRM)	79.93	13.76
Esteem	30.11	5.54
Control	18.38	5.18
Competence	31.44	5.74

Scores from the SF-36v2 for the total sample shows that all participants scored below the norm-based population mean, indicating that all respondents reported worse physical and mental health than that of the general population. This indicates that caregivers are more likely to have worse health than non-caregivers, and that their psychological wellbeing is more at risk. The first stage positive depression screening, calculated as part of the SF-36v2 scoring software (QualityMetric Incorporated, 2011), indicated that 53% of the participants in this sample came out as 'at risk' compared to 18% of the general population.

3.4.4. Primary analyses

3.4.4.1. H1: The provision of care will have a negative impact on caregivers' ability to sustain and maintain their role.

Contingency table analysis using chi-square test of independence was carried out to evaluate caregiver and CR characteristics, access and awareness of support services to providing care to an PwD. A significant association was found between how often a caregiver is able to leave the house (leave frequency) and the type of dementia of the CR, χ^2 (18) = 50.25, $p < .001$. Sixty-three percent of caregivers who look after a loved one with DAT were able to leave the house at least once a day, compared to 21% with VaD. Dementia stage was also significantly associated with 'stand-in' care, χ^2 (44) = 61.55, $p < .05$. This showed that the majority sought more support in the middle stage (54%), compared to the early stage (12%) and later stages (15%). Paid support was also more likely sought within the middle stage (27%). In the early stage, the majority of caregivers relied on themselves (60%) or family (40%) to provide care when they were absent.

Certain caregiver characteristics were significantly associated with factors related to providing care. The relationship between care length and employment status was significant, χ^2 (16) = 28.01, $p < .05$. The majority of caregivers are retiree's (66%), only a few were in part-time (15%) or full-time (5%) employment at 5 years or more of providing care. The relationship with the CR's and type of care provided was significant, χ^2 (40) = 62.18, $p < .05$. Wives offered the least physical support (12%), whereas husband offered care across all types (47%). Physical health problems and care type was significantly associated, χ^2 (78) = 117.1, $p < .01$. Sixty percent of those who reported no physical health problems provided care across the range of different care types required for their CR. The relationship between the ability to leave the house (leave frequency) and access to transport was significant, χ^2 (27) = 57.27, $p < .001$. Having access to their own transport enabled caregivers to leave the house more frequently, at least 67% were able to leave once a day compared to 7% who were reliant on public transportation.

Five MLRs were performed, one for each providing care factor (i.e. care length, care type, whether care is shared, frequency of leaving the house and having a stand-in when the caregiver is absent). The predictors included the scores on the PRM, PCS and MCS. The overall model for 'care type' was significant, χ^2 (24) = 46.83, $p < .01$. The reference category for the outcome variable was caregivers who provided 'all range of care types' (personal care, domestic care, companionship, physical support & medical or mental health support); each of the other categories were compared to this reference group. According to this MLR model, type of care provided was negatively related to the PCS (b = -0.18, Wald χ^2 (1) = 4.99, $p < .05$). The results suggest that the higher the PCS score, the less likely caregivers will perform care tasks that involve domestic care, companionship and medical or mental health care compared to all range of care types, (OR = 0.84; 95% Confidence Interval (CI) = 0.72, 0.98). A full breakdown can be found in Appendix K.

No other significant effects were found between the predictor variables and other remaining factors related to providing care, $p > .05$.

3.4.4.2. H2: Caregivers with higher psychological resilience and wellbeing (physical and mental health) outcomes will be more likely to be aware of, access and use available support services.

Contingency table analysis using chi-square test of independence was carried out to explore the relationship between factors related to support services used and factors related to access and awareness of support services. A significant association was found between support services used and how often paid support is utilised (frequency of paid support), χ^2 (104) = 131.94, $p < .05$. Sixty-seven percent who did not utilise paid support accessed the Admiral Nurse Service, compared to 17% who had paid support every day.

The relationship with support services not used and when caregivers were made aware of services was significant, χ^2 (30) = 47.27, $p < .05$. Forty-two percent were aware at diagnosis of services, although the majority were not using carer support (38%) and memory services

(13%). No significant relationships were found between alternative support service used and factors related to being aware and accessing support services ($p > .05$).

Three MLRs were performed, one each for the three categories for caregiver's engagement with support services (i.e. support services used, not used and alternative services used). The predictors included the scores on the PRM, PCS and MCS. Scores on the PCS, MCS and PRM significantly improved the fit between the model and predicting support services used, χ^2 (18) = 37.71, $p < .01$. The reference category for the outcome variable was 'no services used / indicated'; each of the other categories were compared to this reference group. The MCS was positively related to support services used ($b = 0.25$, Wald χ^2 (1) = 4.54, $p < .05$). This suggests that higher scores on the MCS (OR = 1.29; 95% CI = 1.02, 1.62) significantly increase the probability of using some form of support services available, compared to using no services at all. Results showed that PRM and PCS were not significant predictors, $p > .05$. No other significant effects were found between the predictor variables and other categories related to caregiver's engagement with support services, $p > .05$. A full breakdown can be found in Appendix K.

3.4.4.3. H3: Being aware of, accessing and using available support services would have a positive impact on caregiver's ability to provide care.

Results from the survey indicate that at least 87% of participants used services available, compared to 42% who reported that they did not use support services. Fifty-one percent reported that they used alternative support services.

Contingency table analysis using chi-square test of independence was carried out to evaluate caregiver's use, awareness and access of support services with factors relating to providing care to a PwD. There was a significant association found between whether caregivers have paid support and if care is shared, χ^2 (5) = 27.87, $p < .001$. The majority were lone caregivers who did not have paid support (85%), compared to 15% who did have paid support. Sharing care was also significantly associated with funding and frequency of paid support, χ^2 (15) = 45.12, $p < .001$ and χ^2 (20) = 39.12, $p < .01$, respectively. Fifty percent of paid care was funded privately, compared to 13% that was funded through professional means (i.e. Social Services). Lone carers were less likely to leave the house (7%), whereas those who had support from paid care (39%) and family and friends (23%) were more likely to be able to go out at least once a day.

Type of care provided was significantly associated with support services reported as not being used, χ^2 (24) = 37.18, $p < .05$. Carer support was reported as the highest support not used (37%) across all types of care provided, compared with 5% who did not use paid care or professional support (5%). No significant relationships were found between alternative support service used and factors relating to providing care ($p > .05$).

3.5. Discussion

The aim of the first phase of this study was to highlight and establish the provision of services available within the sample area and gain an overall indication of the impact on their psychological resilience and wellbeing. Further to this, the awareness, access and use of available formal support was also explored. A postal survey was utilised to gather information from known dementia caregivers in The Borough. Below, each of the hypotheses will be discussed in relation to the findings.

3.5.1. H1: The provision of care will have a negative impact on caregivers' ability to sustain and maintain their role.

The results indicate, overall, that caregivers reported worse physical and mental health outcomes compared to the general population. The findings from the first stage depression screening, as calculated by the SF-36v2 scoring software, also indicate that caregivers are at a higher risk for developing mental health problems. This provides support for the hypotheses that provision of care would have a detrimental impact on the psychological wellbeing of dementia caregivers. These findings are consistent with previous outcomes that dementia caregivers are more likely to report increased physical and mental health problems than the general population (Pulsford & Thompson, 2013).

Type of care tasks were significantly associated with relationship type and reported physical health problems. Wives were less likely to perform physical tasks compared to husbands. Moreover, the results indicate that, higher physical wellbeing (PCS) is predictive of the type of care tasks performed. Being physical well and able indicates that caregivers are more likely to perform care tasks that involve personal care and physical support to a greater extent than just providing companionship or domestic care. Therefore, caregivers who struggle with their physical health abilities are less likely to carry out tasks that involve greater physical ability, for example personal care tasks.

A significant difference was found between the type of dementia of the CR and how often a caregiver is able to leave the house. Different types of dementia may provide different complexities and demands on the caregiver, requiring more supervision, therefore, caregivers will be less likely to leave their CR without support. Other findings of interest to note is, that caregivers having access to their own transport increases the opportunities that they have for leaving the house, compared to those who were reliant on public transport. Rather than having to rely on set times or transport delays, for example due to long bus journeys, caregivers who have access to their own transport are able to be more flexible, in terms of judging times best suited to leave or to return quickly if necessary.

A significant relationship was also found between care length and employment status. As dementia affects the majority in later life and is a progressive condition, it is likely that caregivers have taken or are near retirement, especially as the majority are also more likely to be spouses, rather than ACCs who may still be working.

Overall, the results from Phase I supports the first hypothesis that provision of care will have a negative impact on caregivers' ability to sustain and maintain their role.

3.5.2. H2: Caregivers with higher psychological resilience and wellbeing (physical and mental health) outcomes will be more likely to be aware of, access and use available support services.

The results indicate, overall, that higher scores on the MCS is predictive of caregivers utilising a range of support services, more so than higher scores on the PCS or PRM. This suggests that mental wellbeing has some positive effects on caregivers use of support services (Ashley & Kleinpeter, 2002). No significant relationships were found between access and awareness of services, psychological resilience and wellbeing factors.

Overall, the results provide partial support for the second hypothesis. Higher mental wellbeing has been found to have more of an effect in relation to caregivers being more aware, accessing and using available support services, than physical wellbeing or psychological resilience outcomes.

3.5.3. H3: Being aware of, accessing and using available support services would have a positive impact on caregiver's ability to provide care.

The results indicate that, overall, the majority of participants used services available (87%). A limited association, however, was found that knowledge of, having access to, and using support services would have a positive impact on providing care to a PwD.

A significant association was found between whether caregivers had paid support and whether care was shared. Sharing care appears to have a positive benefit, as caregivers are able to leave their CR and go out more often, than lone caregivers, utilising support from either paid care or family and friends.

Overall, the results provide limited support for the third hypothesis. Funded paid support and whether care was shared, was found to increase the likelihood that caregivers were able to leave the house.

3.5.4. Limitations

There were several limitations to this phase of the study, which will be discussed in Chapter 5, Discussion.

3.6. Conclusion

The first phase of this study used a quantitative methodological approach to investigate the experiences of dementia caregivers, in relation to their psychological resilience and wellbeing. Awareness and access to available support services were also considered, including factors influencing the provision of care.

Few studies, to date, have investigated psychological resilience, psychological wellbeing (HRQoL), and their impact on seeking and using support services by dementia caregivers. Overall, the findings from this phase of the study support the hypotheses to a large extent. The results also support previous research findings on dementia caregiver experiences; however, generalisability should be approached with caution. This will be discussed further in Chapter 5, Discussion.

Chapter 4

Phase II: Qualitative approach

4.1. Introduction

Caregiver responses to tasks and demands of providing care are individualistic (Ingebretsen & Solem, 1997). Their ability to cope, adjust, accept and handle demands all differ depending on psychological, biological and social factors that have honed their personality, experiences and abilities (Ingebretsen & Solem, 1997; Zarit & Edwards, 2008). It is, therefore, important to consider individual responses that incorporate their lived experiences of providing care (Gottlieb & Wolfe, 2002). It is also important to understand the perceived needs of caregivers at different stages of the caring 'career' (Proctor, Martin & Hewson, 2002).

An abbreviated introduction to Chapter 4 is presented, for a more in-depth review of the literature, please see Chapter 2, Systematic review.

4.2. Phase II

This study utilised a mixed methodological approach. Through a sequential, rather than a concurrent design (Creswell et al., 2011; Hanson et al., 2005), the second phase aims to elaborate on the results of Phase I (see Chapter 3: Phase I: Quantitative Approach). The use of a qualitative methodological approach to follow-up the postal survey could contribute a realism and validation to the quantitative method (Allport, 1942), as well as lending an in-depth insight into the caring experience. This approach lends itself to an empirical phenomenological methodology and has the advantage of providing rich descriptions of individual experiences, especially how people make sense of the world and how they manage certain conditions (Coyle, 2007).

> "… it is a uniquely sensitive and powerful method of capturing the experiences and lived meaning of the subjects' everyday world. Interviews allow the subjects to convey to others their situation from their own perspective and in their own words" (Kvale, 1996, p.70).

Interviews will offer an opportunity to explore the subjective experiences of caregivers further, to compliment and provide more in-depth meaning to findings gathered in Phase I. Especially in terms of offering a greater understanding of how their role as a caregiver manifested and their understanding as this evolved. The outcomes from the postal survey were used to select and recruit suitable participants to the interview process, and to direct and inform questions in the semi-structured interview.

Potential interview candidates were identified based on their scores on the SF-36v2 and PRM. Interview questions were identified through the quantitative results that necessitated further expansion. Elements such as the relationship with the CR, type of care provided and how long they cared for the CR were highlighted as significant predictors. Being a lone caregiver, the type of care provided and their ability to leave the house was also highlighted as potentially impacting on caregiver's wellbeing, as well as having worse health compared to that of the general population.

Furthermore, the findings from the survey suggest that caregivers were confused with what services were available, indicating that they were 'un-coordinated' and 'hidden'. If caregivers were aware of support services, they reported that they had problems utilising these services. Open-ended questions would allow for participants to extrapolate on this factor further; sharing whether these support mechanisms had been helpful and offer an assessment and evaluation of available support in meeting their needs. This would also provide an opportunity for caregivers to voice their opinions and recommendations for future services. This may be useful to help inform service development initiatives in the future.

The following areas were, thus, identified, based on the findings in Phase I for further exploration, and questions were constructed around these factors: evolving role as a caregiver; the physical and mental health impact of providing care; their awareness, evaluation and utilisation of support services; and, based upon their experiences, recommendations for future interventions.

The rest of this chapter sets out the method and results for Phase II.

4.2.1. Research questions

The following sub-research questions (RQ) were formulated to inform the second phase of this study:

RQ1: What factors influence individuals to modify their caregiving role over time?

RQ2: To what extent do psychological resilience and wellbeing (physical and mental health) factors impact on caregiver's perceptions of providing care?

RQ3: What factors facilitate or hinder caregiver's engagement with support services?

RQ4: From their experiences, what future interventions would caregivers suggest that would improve the support for those providing care to a family member with dementia?

4.3. Methodology

4.3.1. Design

A cross-sectional semi-structured interview was designed to investigate the subjective experiences of dementia caregivers.

4.3.2. Participants and recruitment

A summary of the participant characteristics are displayed in Table 10.

A criterion sampling method was used to recruit eleven caregivers (Patton, 2002), from the Phase I participants, who had provided contact information on the consent form; if they were willing to be approached for an interview. All participants recruited for an interview had provided telephone numbers and permission for contact.

Table 10

Demographic characteristics of Phase II participants

Interview participant	Age	Sex	Dementia type	Relationship with CR	CR Age	Group	Contact information provided
1	47	M	DAT	Son	83	1	Telephone
2	67	F	Unknown	Wife	67	1	Telephone, E-mail
3	51	M	DAT	Son	83	2	Telephone
4	65	F	DAT & VaD	Wife	70	3	Telephone
5	81	M	DAT	Husband	76	3	Telephone
6	80	M	DAT	Husband	78	4	Telephone, Address
7	54	F	DAT	Daughter	87	4	Telephone
8	53	F	VaD	Daughter	85	4	Telephone
9	60	F	DAT	Niece	89	1	Telephone, E-mail
10	80	F	Unknown	Wife	83	4	Telephone
11	58	F	VaD	Daughter	92	3	Telephone

Note. CR = Care recipient, M = Male, F = Female, DAT = Dementia of the Alzheimer's type, VaD = Vascular Dementia.

4.3.2.1. Selection procedure

Participants, who provided consent, were invited for an interview based upon their scores on the PRM and SF-36v2. Those who scored below the PRM calculated mean (mean = 79) were considered as showing low psychological resilience, whilst scores above the mean was taken as high psychological resilience. On the SF-36v2, those below the norm (score = 50) indicated a low health score, whilst those above 50 were viewed as high health scores. Table 11 shows the number of potential interview participants for each group

Table 11

Matrix grid of potential interview participants (n=24)

	High resilience	Low resilience
High health & wellbeing	(1) 3	(2) 1
Low health & wellbeing	(3) 4	(4) 16

Note. Group indicated in brackets.

A large number of potential interview candidates (*n*=24) were indicated through this selection procedure, with group 4 having the greatest number of potential interviewees (*n*=16). Four participants were randomly selected using the 'case selection' procedure in SPSS. This interview selection decision was based upon the potential large number of participants in group 4 and the resultant potential bias this could introduce. Selecting four interviewees was considered proportionate in relation to the other three groups, where four was the largest number across the groups. Therefore, twelve caregivers were approached for an interview, and unfortunately, one participant, who provided a postal address only, did not respond to the invitation (Appendix R). They were, therefore, withdrawn from the study (Group 3). All other participants were contacted via telephone.

4.3.3. Measures

4.3.3.1. Semi-structured interview

The semi-structured format allowed for flexibility because:

> "it has a sequence of themes to be covered, as well as suggested questions. Yet at the same time there is an openness to changes of sequences and forms of questions, in order to follow up the answers given, and the stories told by the subjects" (Kvale, 1996, p. 124).

An interview guide was developed, based on the literature on dementia caregivers and the elements identified in the postal survey (Braun & Clarke, 2013). A pilot interview, of the first draft of questions, was carried out by the researcher and a Trainee Counselling Psychologist. This enabled a check for the suitability and flow of the interview schedule. Through this piloting process, questions that appeared ambiguous or unclear were reformulated. See Appendix M for final interview guide used.

The guide included four domains: (a) caring context, (b) impact of caring, (c) awareness, evaluation and utilisation of available support, and (d) future interventions. Caregivers were also asked probing questions to expand further on a topic, if appropriate. Following each interview, field notes were made by the researcher about the interview: the caregivers experiences of providing care and any reflexive thoughts observed by the interviewer.

4.3.4. Ethical considerations

A second ethical application was submitted, in order to approve the Phase II process and the final interview guide. This was granted by the Faculty of Education, Health and Wellbeing Ethics Panel, The UoW (Appendix N).

4.3.5. Interview procedure and data collection

Each participant was contacted via telephone and were sent an interview invitation pack. This included: a 'confirmation of interview' letter; a participant information sheet; a consent form and a withdrawal form (Appendix O). One interview was conducted over the telephone, for which consent and debrief procedures were verbally provided, recorded and retained for audit purposes. They declined receiving further information via post.

For all interviews, the researcher introduced themselves, briefly outlining the aims of the study, checking and collecting the consent forms. The telephone interview was the first in Phase II, which was recorded via the 'Call Recorder' App, version 5.26 on an Android device, Samsung S5 mobile phone. All the other interviews were conducted face-to-face and recorded on a Phillips DVT3500 digital voice recorder. Digital files were transferred to a password protected computer.

Each interview was transcribed verbatim, using an orthographic style (Braun & Clarke, 2013). An orthographic transcription focusses on what was said, not how it is said, and is the most common form of transcription used in qualitative research (Howitt, 2013). Transcriptions are produced dependent on the purpose of the analysis, therefore, a more phonetic or paralinguistic transcription style, like the Jeffersonian approach, was not deemed appropriate for this study (Braun & Clarke, 2006, 2013; Howitt, 2013). All personal, identifiable information was removed or anonymised during this process.

Digital recordings and typed transcripts of the interviews were kept on a password protected computer, within a secure cupboard in a locked room. On completion of the study, all personal and identifiable information was destroyed. Raw data will be kept securely for up to three years by the University of Wolverhampton, before it will be destroyed.

4.3.5.1. Debrief

Debriefing was considered important, especially with what may be deemed a vulnerable participant group and the sensitive content of the research. Therefore, an appropriate debriefing procedure was put in place, available even after the research was completed (Shaughnessy, et al., 2000). After the interviews, the researcher 'checked-in' with the participants for any signs of distress. A debrief form (Appendix P) and an information guide (Appendix Q) was given to all face-to-face interview participants, which included information about services that are available in The Borough, for people affected by dementia.

4.3.6. Data analysis

The transcribed interview data were analysed using thematic analysis (TA; Braun & Clarke, 2006). Braun and Clarke (2006) have argued that TA, although, essentially a 'poor cousin' of qualitative methods, is the basic foundation for other methods; such as, discourse analysis. Braun and Clarke have attempted to fill the current gap, regarding the use of TA as a "poorly demarcated and rarely-acknowledged, yet widely-used qualitative analytic method" (p. 4), by producing a step-by-step guide. Their efforts have succeeded in defining TA as a widely used and accepted approach within psychological and social science research (Coolican, 2014).

TA was chosen as appropriate for this study, due to the flexibility and accessibility of this approach for analysing qualitative data, along with its adaptability to investigate a range of research questions (Braun & Clarke, 2013). Additionally, it is regarded as potentially offering a rich and detailed account of the data, that can highlight similarities and differences across the data set and allow for psychological interpretations (Braun & Clarke, 2006). Grounded theory (Glaser & Strauss, 1967), a more common analytic method, was not considered appropriate, because the interview questions and potential themes were developed 'a priori' to the data analysis (derived from Phase I data). Similarly, discourse analysis was not deemed suitable, since more emphasis is placed on 'what was said' rather than 'how it was said' (Howitt, 2013).

A series of six different phases have been outlined by Braun and Clarke (2006), as a qualitative analysis guideline to support the TA process and has been adopted for this study. Moreover, Braun & Clarke suggested a concise 15-point checklist of criteria to consider for conducting a "good TA" (Braun & Clarke, 2006, p. 286). Table 12 shows the procedure followed within this study, demonstrating the six stages outlined by Braun and Clarke (2006); as well as incorporating elements from the 15-point checklist. Coding and identification of themes were conducted at a latent level, utilising a 'framework approach' (Ritchie & Spencer, 1994), ensuring that the analysis was theory-driven. The qualitative analysis programme, NVivo Pro, version 11 (Quality Solutions Research [QSR] International, 2017), was used to support data analysis.

For inter-rater reliability, some extracts were reviewed by a MRes graduate, experienced in TA. They were provided with a code book and random extracts were analysed. This produced a 83.33% congruence between raters, indicating a "good level of agreement and supposedly 'reliable' coding" (Braun & Clarke, 2013, p 279).

4.3.7. Reflexivity

Reflexivity was adopted in this study, to allow the researcher to recognise their own interpretations of the results and the impact that their own experiences and knowledge may have on the analysis of the data (Coolican, 2004). This will be picked up in more detail in Chapter 5, Discussion, which will be incorporated in a reflective discussion on the process of the whole study.

4.4. Results

4.4.1. Participants

Twelve participants were approached for an interview and eleven were used for the purposes of data analysis below.

Caregivers were between 47 and 81 years of age (*M* = 63.27, *SD* = 3.73), where more than half were either female (64%) or caring for a parent (55%). In respect of employment: 46% of the caregivers were retired (*n*=5), 36% were working full-time (*n*=4), 9% part-time (*n*=1) and 9% were self-employed (*n*=1). Fifty-five percent had no paid support, compared to 45% who did receive paid support.

The interviews took place between May 2016 and September 2016. Interviews lasted on average for 48 minutes. Characteristics of the interview process are displayed in Table 13.

Table 12

Phases of Thematic Analysis

Stage	Description and criteria
1	Familiarisation with interview data and transcription (data immersion): • Interview data transcribed from recorded audio, data anonymised. • Original audio recordings checked against transcripts for ‘accuracy’. • Transcriptions re-read and initial ideas noted down.
2	Generating initial codes: • Printed transcripts were re-read and initial interesting features were manually coded by writing text in the margin. • Printed transcripts were re-read to highlight any potential patterns and noted in the margin. • Digital transcripts were read through again and NVivo was used to code further significant patterns. • Transcripts were read through yet again, manual codes were merged with NVivo data. • Data set given equal attention, within a thorough, inclusive and comprehensive approach

3	Searching for themes:
	• Two iterations of manual coding and one using NVivo software to condense and reduce codes were completed.
	• Data identified from the transcripts have been coded and collated using NVivo.
	• Codes were written on ‘post-it’ notes, this enable codes to be examined simultaneously and allowed:
	    • Similar codes to be collapsed,
	    • Codes to be grouped,
	    • Groups of code to be evaluated for consistent patterns and themes.

4	Reviewing themes: • Links and coherent patterns identified to form overall themes. • Data within themes cohere together meaningfully. • Themes accurately reflect the data set as a ‘whole’.
5	Defining and naming themes: • Themes checked against each other and against the original data set. • Themes are internally coherent, consistent and distinctive. • Themes are clearly defined and provided with an appropriate name.
6	Producing and writing the report: • Vivid, compelling extract are selected as examples to showcase interpretation of data. • Analysis of data relates back to research hypotheses and relevant literature.

Table 13

Interview process characteristics

Interview participant	Interview process	Location of interview	Interview conducted	Group
1	Telephone	N/A	May 2016	1
2	Face-to-face	Home	May 2016	1
3	Face-to-face	Home	May 2016	2
4	Face-to-face	Home	May 2016	3
5	Face-to-face	Home	May 2016	3
6	Face-to-face	Home	June 2016	4
7	Face-to-face	Home	June 2016	4
8	Face-to-face	Home	June 2016	4
9	Face-to-face	Home	July 2016	1
10	Face-to-face	Cafe	August 2016	4
11	Face-to-face	Home	September 2016	3

Note. Group 1: High resilience, high health & wellbeing; Group 2: Low resilience, high health & wellbeing; Group 3: High resilience, low health & wellbeing; Group 4: Low resilience, low health & wellbeing.

4.4.2. Overview of findings

Analysis of this data generated seven main themes, with a number of codes identified for each (see Table 14).

Table 14

Summary of themes and codes identified

Themes	Codes	Description
Diagnosis facilitates access to support	Trigger leading to diagnosis	Not just old age, trigger to seek help / diagnosis, visit to GP to initiate diagnosis process.
	No diagnosis = no support	Diagnosis difficult to get, fight for support, diagnosis got the ball rolling, access to support 'snowballed'.
Relentless deterioration	Losing battle	No hope, not get any better, inevitable decline, gradual process, never ending.
	Escalation of role	Expanding circle of tasks, having to do everything for CR, cannot be left unsupervised, taking on more and more.
	Encumbrance	Reduced time to do other activities, becoming more limited, CR priority, need to be flexible to fit in with CR, things getting too much.
	Entrapment	Constant 24/7, reduced ability to get away, tied up, stuck, totally committed to caring, everything is on CG.
Caught in the middle	Perpetual commitments	Moving from one problem to another, dealing with extra problems, balancing existing and new commitments.
	Reality gap	Loss of previous life, change of future plans, trying to find a balance.
	Torn loyalties	Juggling, caught in the middle, trying to keep the peace.
Unsustainability	Acknowledgment of fallibility	Recognising need for quality respite, awareness of looking after self, realisation of own mortality, complete break required, hard work.
	Maintaining role	Reach a stage no longer able to care, how long is caring sustainable, activities that helps to sustain role.
Adaptation, adjustment & effects on caregiving	Metamorphoses of care recipient	Unwanted behaviours, old vs new, CR becoming unpredictable and an unknown person, change in roles, regressed child, CR living in own world.
	Learning curve	Constantly adapting as it progresses, finding what works best, compromising to see what works.
	Responsibility for superior care	Sense of obligation to provide good quality care and look after CR.
	Personal misgivings	Having self-doubt of doing the right thing in the circumstances, choosing what's best to do, making life as good as possible for the CR.
Coping strategies	Removing self	Having protected 'me' time, getting away from the house or going on holiday, detaching emotional self.
	Having an outlet	Having someone to talk it through with, family confidant, emotional release, informal confidant and advisor.
	Organisation & planning	Being an organised person, forward planning, continually reviewing situation, develop techniques.
	Plodding on	Taking it day by day, dealing with it as it arises, went with it, optimism.
	Using support networks	Support from family, friends and other support networks.
	Other coping strategies	Keeping busy, having paid support in, focussing on positive memories, meditation strategies.
Evaluation of support services	Support experiences	Inequality of services, lack of co-ordination, impact of financial constraints, grateful for support services, surprised at support available.
	Support preferences	Importance of continuity, type of contact, provision of information, take individual context into account.
	Support barriers	Reluctance of CR to access support, logistics inflexible, fitting it in, reluctance to give up independence.

Note. CG: Caregiver; CR: Care recipient.

Each of the themes and related codes are discussed, below, and illustrated with verbatim extracts.

4.4.3. Diagnosis facilitates access to support

This theme reflects caregivers need for a diagnosis to be made, in order for formal support to be accessed. Two codes interpreted from the data contributed to this theme. Firstly, seeking a diagnosis was, for the majority, triggered by a suspicion that something was wrong, which involved several incidents of odd and forgetful behaviour on the part of the CR. Secondly, interviewees believe that a diagnosis ‘opens a door’ to support services and access to professional expertise, emphasising that without one there would be no support, leaving them to struggle on their own.

4.4.3.1. Trigger leading to diagnosis

Nine participants (82%) could identify a series of events that reflected an abnormal deterioration, which they could not relate to normal aging, *“it wasn’t just old age” (Interview Participant (IP) 4, Line (L) 10).* As difficulties became more pronounced and frequent, caregivers seemed to become suspicious and concerned as to the causal factors behind the behaviour of their CR.

> *“Well, I think, when she first came to live here, we didn’t really think there was anything much wrong, apart from getting a bit older, a bit slower, and forgetful, as we all do. And, then it got to a point where the forgetfulness was a little bit more than just forgetfulness, it was a little bit of confusion as well, and asking a question ten minutes after you’d answered it.” (IP 9, L 5-12).*

> *“Just behavioural problems and memory. And then, obviously, it became noticeable that she was forgetting how to do things.” (IP 11, L 16-18).*

> *"Well, how it started, my mum is 82, and she was having these episodes, basically, of forgetting things and I thought, well, it's old age. Anyway, it got worse ..." (IP 1, L 13-16)*

A few of the participants described specific situations that showed *"how awkward things" (IP 5, L 22)* had become, suggesting events may go unnoticed or are compensated for until behaviours cannot be explained away by *"old age" (IP 1, L 15)*.

> *"Well, this happened about nearly three years ago, it became apparent. We were on holiday in America, a cruise in the Caribbean ... and we got back to London, and she wanted to know what we were doing there. She'd completely forgotten that we'd been in America and the Caribbean, for a fortnight." (IP 5, L 13-15; 200-203).*

From the examples provided by interviewee's, most appear to be reflective, using hindsight, to illustrate the larger difficulties that arose, which now seem obvious to them. This also showed some of the realities of the situation and the depth of struggle that the CR must have been experiencing, prior to a diagnosis being made.

> *"... it was fairly obvious that she'd started to deteriorate prior to that. But, we found out that she was getting in trouble with all the utility bills, and things like that. Then, she used to drive ... Then, one day, she came back in tears, she'd lost her way, and that was when we first realised that she had got a massive problem." (IP 6, L 6-10; 16-18).*

> *"... you just knew things were very wrong, you know, it started when she couldn't drive, because she couldn't remember how to drive. And then, it was, she couldn't remember how to get money out of the cash machine, and the key indicators of things that she'd been able to do, but were relatively new skills to her, she was losing." (IP 11, L 156-162).*

> *"... it was just that he was forgetting things. But then, as I say, he started doing weird and wonderful things, and saying weird and wonderful things." (IP 4, L 316-319).*

As difficulties became more noticeable over time, decisions were made, usually by the primary caregiver or close family members, to seek professional support, the majority accessing their GP, as their first port of call. This in turn led to a referral for an assessment and, for ten of the eleven participants interviewed, a diagnosis for their CR.

> *"So, we went down to see the doctor, and she suggested an appointment at the Memory Clinic ... After that, she said, I'm going to refer you to the Dementia Care Services, and get them to come out and do a proper assessment, which they did ... The nurse came out, a couple of weeks later, you know, she'd obviously collated all the information she'd got, came back, and she told us she'd got Alzheimer's." (IP 9, L 20-21; 34-36; 70-73).*

> *"We had the Memory Service come, who told me, when they came to see her, that she had vascular dementia." (IP 11, L 18-20).*

> *"Anyway, we got in touch with the doctor ... Eventually, the doctor referred her to the memory doctor ... And, he assessed her, and it came back, conclusion, she'd got the early stages of dementia." (IP 1, L 24; 29-30; 32-33).*

One participant described the difficulty of getting a definitive diagnosis. They also mention being hopeful that it would be depression, rather than dementia; although *"it turned out over the years, it was." (IP 3, L 413).*

> *"... in the early stages of these things, it's very difficult to make a definitive diagnosis, isn't it, and I think it was really quite early stages of things. And, initially, I wouldn't say it was put down, but may be a little bit of depression, and you, sort of,*

> *learn to cling to things like that, because the alternative is a lot worse, isn't it?" (IP 3, L 397-403).*

One interview participant was prompted to seek support for a diagnosis as they attributed some of the CR's behaviour to the normal aging process. This may be indicative of being in a sense of denial, in regard to refusing to acknowledge that their loved one may be deteriorating with a degenerative disease. This would have a more finite outcome than the possibility of depression or it being *"just old age" (IP 7, L 43)*.

> *"... there were things happening, and I thought, is this just old age, and I just happened to be talking to someone at work, and they said, you know you can have a test for dementia ... So, I went to the doctors ... she was diagnosed with Alzheimer's." (IP 7, L 42-46; 49; 52-53).*

In this code, participants described either, noticing a gradual deterioration in the actions and behaviours of their CR, or noted specific incidents or events that led them to question whether this was part of the normal aging process. This ultimately prompted them to seek out further support and triggered the procedure for assessment and diagnosis.

4.4.3.2. No diagnosis = no support

Eight of the interview participants (73%) agreed that without a diagnosis, access to support was very difficult. The GP appeared to be the first point of contact that led to CR receiving a diagnosis and an onward referral to other services.

> *"It was through the doctor, he contacted social services, they set up an assessment team." (IP 1, L 336-337).*

> *"I eventually managed to get him to the doctors, and that started the ball rolling." (IP 4, L 11-13).*

> *"GP was the first port of call, and she said, have you heard of the Carer's Centre, have you got a social worker, and I said, no, to most of these things, because I haven't really." (IP 9, L 1047-1050).*

> *"And, going through the GP, and once you're involved with the services, you become made aware of things." (IP 3, L 426-428).*

> *"When we went to the GP, had his test, and he was referred to the Memory Team, that's when it all started, really." (IP 4, L 845-847).*

Once a diagnosis was received, this led to what some described as a *"snowball effect" (IP 4, l 864)*, where one service would activate another and so on.

> *"I was referred to the Alzheimer's Society, you have to register as a member. The Carer's Society, I'm a member of that, it's all, sort of, snowballed, if you like." (IP 4, L 850-853).*

> *"Social services, or whatever, they'd come in and say, you know you can get help for doing this, that, and the other, and I was going, can you. I didn't realise ... they gave me lots of information and leaflets, I was quite impressed really. Then, I think they must have, I think the first lady from the mental health team, I think she got in touch with the Alzheimer's Society, Association, whatever they are." (IP 7, L 105-108; 123-128).*

For specific support mechanism, such as claiming benefits, it appeared that a formal diagnosis is specifically required, as the following participant reports:

> *"... they said, are you getting all your benefits. And, I said, well, what benefits should I be getting? Is he getting attendance allowance? I said, no. She said, has he had a diagnosis? And, I said, yes. She said, attendance allowance." (IP 4, L 537-539).*

Without a diagnosis, this may create difficulties as one participant shared, *"I found it very, very hard" (IP 11, L 10).* This was exacerbated further, by the consequences of not having information appropriately documented and communicated.

> *"We had the Memory Service come, who told me, when they came to see her, that she had vascular dementia. Unfortunately, they didn't actually convey that to the doctor, and, because ... I assumed that that had gone on my mother's records. It hadn't ... Although the doctor knew she had dementia, and she was receiving care for dementia, it hadn't been formalised. So, every time I've needed something, I've had to fight." (IP 11, L 18-23; 29-32).*

They use the word 'fight', which suggests an ongoing struggle to have support. Further on, in their interview, they reiterate this 'virtual battle', by saying that *"I think the fact that you're fighting to get a diagnosis is very unfair" (IP 11, L 451-451).* They go on to emphasise the need for a formal diagnosis, otherwise, in their experience, support would not be available.

> *"... if you haven't got the diagnosis, you can't get the help. And, although everybody comes in and says, oh yes, yes, that is dementia, until it's actually been certified, as one type or another, then you can't move forward." (IP 11, L 452-457).*

Without adequate support in place or services being aware, can be detrimental to the health and wellbeing of both the CR and the caregiver. The experiences of the following caregiver highlighted that one of the fundamental areas are still being neglected:

> *"I mean, I'm a particularly strong person, and the fact that I couldn't get it done, I'd hate to think how other people are coping. And, they are probably coping with undiagnosed dementia, therefore, they will not get the help and support that they need." (IP 11, L 457-462).*

Once a diagnosis was received, the majority had support and access to services; which *"snowballed" (IP 4, L 853)*. One participant, however, emphasised their struggle to access support services when no diagnosis was formalised.

Overall, the theme of 'diagnosis facilitates access to support' highlights the importance of receiving a formal diagnosis. The data indicates that without adequate support, in place from the outset, the likelihood that caregivers will be at an increased risk for symptoms of depression and anxiety should not be wholly unexpected.

4.4.4. Relentless deterioration

This theme relates to the increasingly intense experience a caregiver undergoes with the deterioration of their CR. As the individual with dementia progresses further with their condition, the role of the caregiver increases. This may involve taking on more responsibilities and tasks, even as it becomes more difficult to manage their individual situations. Essentially the life of the caregiver narrows as time moves on.

4.4.4.1. Losing battle

Ten participants (91%) appeared to describe their experiences as a hopeless struggle, knowing that it can only end in failure. One caregiver described receiving the dementia diagnosis as a *"life sentence" (P4, L 323)*. Furthermore, a dementia diagnosis seemed to evoke highly emotive responses, with participant's using wording that can be construed as negative.

> *"I started out as a carer with a pretty good idea of where this was going to go." (IP 11, L 431-433).*

> *"... then he was diagnosed with Alzheimer's. I think from then on, I thought well, I'm a sensible woman, I know a bit about life, I know what the word Alzheimer's means, so I knew it was, if you like, a life sentence." (IP 4, L 319-323).*

> *"We've had relatives die of cancer, and watched that disease eat them away, and that's physically, this dementia it eats your brain, it just eats it away." (IP 1, L 595-598).*

A sense of helplessness was expressed, in that, they realised the inevitability of their loved one deteriorating and the probable final outcome.

> *"... you were just watching somebody going down a sliding slope, and there was nothing you could do about it, nothing at all .... it's that shock, that initial shock, it's bad enough the patient having it, obviously, the people around the patient are going to see the decline, and everything, in that patient." (IP 1, L 628-631; 636-639).*

> *"I mean, all I can look forward to is [Wife] going downhill, which is soul destroying for me." (IP 6, L 732-734).*

A few use the phrase *"soul destroying" (IP 1, L 640; IP 6, L 734)*, to describe watching a loved one deteriorate down a *"sliding slope" (IP 1, L 629)*, without being able to provide relief. In a sense, they felt that there was *"nothing" (IP 1, L 642)* they could do, helpless, in a worsening situation, *"certainly not going to get better" (IP 4, L 470),* it is most likely *"going to get worse and worse" (IP 5, L 983)*. One participant described no longer looking forward to anything:

> *"There is no light at the end of any tunnel, nothing really to look forward to in a constructive way." (IP 5, L 513-515).*

Moreover, a few participants likened their experience of providing care to a *"constant battle" (IP 2, L 18)*, that seemed to continue relentlessly without an end in sight.

> *"Because, it is never ending, minute by minute, day by day, it's there, constantly. And, you're losing, and losing, and losing, and losing, and losing, and you can only take so much of it, it just grinds you down." (IP 5, L 443-447).*

Some evoke the imagery of a battle, where they live "*trying to get through every day, one at a time. Because, I can't win" (IP 5, L 155-157),* even though it is a *"no-win situation"* (*IP 5, l00-101).*

Some reflect on how *"tiring" (IP 2, L 16)* this process can be *"because it's 24/7" (IP 2, L 16)* and that, as one participant expressed, *"it just grinds you down" (IP 5, L 447).* Despite this, some expressed that they will continue to provide care as best as they are able:

> *"I'll go along with as long as I feel I can. It's, sort of, you know, that's the way it is, that's the way I feel about it." (IP 3, L 175-177).*

There was a realisation expressed that many were *"not really under any illusion" (IP 3, 171-172)*,

> *"... that, at some stage, she'll have to go full time into care, there will probably come a time when I can't handle it." (IP 6, L 603-605).*

In this code, participants used powerful imagery to describe this sense that they were fighting a losing battle, even with the realisation that their CR will only get worse as the condition progresses. The majority expressed the view that, they will continue to look after their loved one until they are no longer able, even though they may feel helpless and the situation continues to decline.

4.4.4.2. Escalation of role

Within the interviews, all participants (100%) expressed a sense that they have experienced an increase in the intensity of their role. Most describe a gradual expansion of their tasks in support of their CR, especially in relation to dependence, *"she's pretty much totally dependent" (IP 3, L 74).*

> *"I mean, whereas before I'd take her shopping, and everything, take her to the bank, she could pay her bills, it was non-existent anymore, it had got to a stage she just couldn't do it. So, I had to take over, make sure the bills and everything were paid, and all the rest of it." (IP 1, L 50-56).*
>
> *"Well, I now do everything ... everything is on me." (IP 2, L 105; 186).*
>
> *"So, there were lots of little incremental points, where one thing deteriorated, and then another thing deteriorated. Until, it got to the point where, I took control of the tablets, took control of the hearing aids, the hearing aid batteries, because they'd be all over the place." (IP 9, L 212-217).*

The increased dependence of the CR on the primary care provider, is described by most as a gradual or slow process, that *"creeps up on you slowly, slowly, slowly, and there's not a massive day to day difference at all." (IP 3, L 210-211).* The caregiver role, therefore, appears to progress without notice, in the majority of cases, as they gradually take on more without being aware.

> *"I was doing things for [Husband], which I wouldn't notice are caring jobs ... And, you suddenly think, oh, because it's always been there ... you don't think. There are lots of people out there that don't notice, or don't class themselves as carers, because they've always been doing it, or it's come on gradually, and they don't notice it's come on gradually." (IP 2, L 427-428; 431-432; 436-440).*

This code demonstrates that the role of the caregiver escalates gradually, over a slow period of time, often unaware that they are taking on more and more daily tasks.

4.4.4.3. Encumbrance

Eight participants (73%) expressed a sense of constraint, as the dependency of their CR increased, creating a greater reliance on them as primary caregiver. They described their own activities as becoming more limited and restricted; with more focus being placed on the needs of their CR.

> *"I don't have a lot of time for anything else, I mean, I don't do a lot of socialising." (IP 1, L 207-208).*

> ***"****I would dearly love him to go into respite care, even if I stopped here, I just want a little bit of time without having to think about [Husband], before I do anything. My prime concern is [Husband], and before I do anything, does he need anything, does he want anything." (IP 4, L 1006- 1012).*

Some participants expressed a sense of *"juggling" (IP 7, 273)* all activities within their lives; catering to other dependents and commitments. The majority of the time, participants mention that the primary focus is on others and their needs come last.

> *"There are other things that I can access with the carers me time, but it's finding the time in between all the appointments, all the slots ... it's all organising for other people." (IP 2, L 330-332; 335-336).*

> ***"****Me in the middle, yes, I don't get any time out. Or, even if I do, I have to run 'round like an idiot ... And, the services, it's as though I'm being awkward, I can't fit them in. No, I actually can't see you, you know." (IP 8, L 95-96; 630-632).*

As the condition develops and progresses, caregivers seem to become more hindered with their obligation to provide care. As described, more often than not, it seems the needs of the CR are prioritised above managing their own interests and occupations. As the following participant described, his commitment to care is impeding on his own interests and ability to do other tasks:

> *"Well, it's been a big problem for me, because I've been very active, physically, in my life ... I'm almost totally committed to looking after her ... It's just the fact that you're tied up so much". (IP 6, L 80-81; 95-96; 642-643).*

They describe a sense of being 'tied up' and having that 'commitment' and reiterating that *"it is hard work" (IP 6, L768)*, when there are potentially other things that they would like to do,

> *"There's jobs outside I'd like to do, and I don't know, it's difficult, it's difficult." (IP 6, L 768-777).*

It is, as if, he is almost stuck between what he perceives he should do and what he would like to do. Seeking and gaining support has also been shown to obstruct the processes of providing care; in that, seeking information on support services are time-consuming and procedures themselves are faulty.

> *"It takes a lot of time to find out what the services are, and I'd probably say, 95% of everything that's been put place, I've managed that through. If I'd have left it to the Government ... we'd still be completing stupid forms, answering the same silly questions, over and over again ... because that's taken an awful lot of time, a hell of a lot of time. And then, of course, you have to phone, and get referrals, you know. Crazy stuff." (IP 8, L 552-555; 556-558; 584-586).*

Participants evoked a sense of burdensome responsibility that as time progresses restricts and limits their own lives. Social, leisure, occupational and other interests are diminished as commitment to care becomes the primary focus.

4.4.4.4. Entrapment

This code emphasises that providing care is a consuming activity. CR become more reliant, over time, and with this increasing dependency, caregivers are 'tied' into putting all focus and energy into ensuring that their loved ones are well looked after.

> *"Being tied. Being restricted. Not being able to do what you want to do. It sounds awful." (IP 2, L 139-140).*

> *"My life has changed completely, I can't do anything, unless I have arranged for a carer to be here. My mother cannot be left for one moment." (IP 11, L 34-37).*

A sense of unfairness and injustice is evoked, as one participant expresses that they are *"angry" (IP2, L 152)* at the situation. Especially, that all participants (100%) found that being spontaneous was difficult and that they could no longer *"just do things off the cuff" (IP 9, L 870)*. Furthermore, increasing restrictions limited the span of activities and events that they could participate in.

> *"... one day you totally do whatever you want, whenever you want, to having the responsibility of being a carer, it doesn't happen in 24 hours." (IP 3).*

> *"The biggest impact? Well, not being able to do what we really want to do, I think. Because, we have got restrictions, we've got lots of restrictions, we can't go out ... I used to go down to see my brother for a night, and come back the next day, I'd never stay longer, I don't get that now." (IP 2, L 180-183; 61-64).*

One participant appeared to be very accepting of their need to restrict leisure activities, emphasising an adaptive response to the situation as it fluctuates, accommodating as the need arises.

> *"I don't go fishing anymore. But, it's not the end of the world, is it? I just go and have a game of golf. The same again, I wouldn't go off to [town] playing golf for eight hours or ten hours, if it needs to be done it needs to be done, doesn't it?" (IP 3, L 268- 273).*

Compared to the ACCs, spouses (45%) were more likely to express that they did not have a break from their CR, as they spent the majority of time together. The phrase '24/7' was used by all spouses to emphasise that there was *"no escape" (P4, L 940).*

> *"I think it's totally different when it's your spouse, because there is that 24/7, there is no escape route." (IP 4, L 938-940).*

> *"... it's very, very difficult because there's just the two of us, and we're stuck 24 hours a day, seven days a week." (IP 5, L 70-72).*

> *"It's the fact that you're committed for 24 hours a day, that's the biggest problem." (IP 6, L 235-236).*

Furthermore, this idea of being committed for '24/7' was also expressed as being involved with the CR, even when they were not together. Two participants stated that, they were unable to *"switch off" (IP 8, L 358)*, even when they were away, as they would worry about the CR, which does not afford them quality respite.

> *"I mean, every year we've been away on holiday, there's always something happened, one has had a fall, or something. There's always something occurred, and*

you're always on edge, on holiday even, you know, what's going on, what's going on. It's crazy." (IP 1, L 493-498).

"... nevertheless, one does need time out, and quality time ... Where you're not thinking, I hope they're alright, did they remember to take this pill, did they do this, you know." (IP 8, L 111-112; 116-118).

This code emphasises a state of entrapment as a response to their perceived duty and commitment to care, which as it increases demonstrates a loss of freedom; as they become *"immersed in it, 24 hours a day" (IP 9, L 1262).*

Overall, participants shared experiences of being caught up in an ever-increasing commitment to providing care, becoming more restricted in their own lives.

4.4.5. Caught in the middle

This theme relates to caregivers expressing their view of being 'caught in the middle'. Most participants expressed a feeling that they stood between their own desires, commitments and others that they wished to please. They face difficult decisions with regards to balancing their own life and taking on an increasing role in that of their CR's lives; whilst ensuring that they continue with their current enterprises.

4.4.5.1. Perpetual commitments

Ten of the participants interviewed (91%) indicated a need to balance established and current commitments, for example, employed work with the escalating activity of providing care to a PwD. Some participants have described the difficulty of balancing their role as primary care provider and other tasks. As this participant described,

> *"... it's all a worry, because you're just constantly worrying, about having to do it on top of ... I mean, my job is quite active ...and you come home absolutely exhausted." (IP 1, L 306-3308; 310).*

This suggests potential feelings of guilt and self-doubt that manifests, as they try to find a balance. This is further illustrated by,

> *"I feel like sometimes, you know, I can't do enough, but I can only do so much, because it's no good me wearing myself out, I'll be no good for no one, because I've got a family, and all the rest of it myself." (IP 1, L 116-120).*

Some participants have indicated, however, that some commitments are necessary to the provision of maintaining and providing a good environment for care. Not only as a means for physically ensuring that all needs can be met, also as a way of accessing support and for the caregiver to maintain a sense of perspective.

> *"Yes, that's why we have the carers in, they're here when I'm at work, because I have been the only income generator for 11 years. So, if I don't work, we don't get to stay where we live, so I need carers in while I'm at work." (IP 11, L 221-225).*

> *"I've still got my commitments, looking after my grandson ... that's fine because I want to go and see him ... and it helps my daughter out because, obviously, she's got to pay for childcare." (IP 9, L 916-917; 919-920; 921-923).*

> *"I think there's lots of support out there, it's about being able to access it, and having the time to get to it. If I wasn't working it would have been different, I think having a job was, you know. But, that probably kept me sane as well, having a job." (IP 9, L 1307-1311).*

The health of the caregiver is reported by the interviewee's as another aspect, that is important in establishing a balance when providing care. This was seen, as a perpetual commitment, that appears to be a necessary obligation for participants to maintain and oversee. The difficulties brought about by their own health issues may also impede caregiver's ability to carry out tasks and expected roles when providing care, for example, one participant described their osteoarthritis in their hands as preventing them from carrying out support with dressing.

> "And, trying to tie shoelaces for [Husband], and this sort of thing, pulling shoes, I can't get him to understand that, literally, I can't do it, you know what I mean." *(IP 4, L 172-175).*

Serious health complications are described by some participants that would be classed as disabling in their own right; especially, as physical exhaustion is a main feature for most.

> *"I've got my own health problems … When mum was first diagnosed, in 2013, I was just coming to the end of my first lot of treatment, I think. No, that's not true, 2014, that was it, I was still having treatment, I was still have injections in my leg, but I still get tired and stuff like that, and I was trying to work as well." (IP 7, lines 60-61; 240-245).*

> *"But, one of the biggest things is, I suffer with ME, and sometimes I get to the stage where I'm absolutely and utterly exhausted". (IP 4, L 160-163).*

> *"Because, I'm terminally ill, I have leukaemia and, sadly, my husband passed away, so …" (IP 11, L 83-85).*

The health of the CR can also be unpredictable, especially outside of the expected deterioration of the dementia syndrome diagnosed.

> *"And, basically, since he was diagnosed in the early stages, I've just been looking after him. But, as I say, it's an unknown quantity, he's now in the process of being diagnosed with Parkinson's." (IP 4, L 26-30).*

In addition, some participants have expressed that a series of difficulties would occur, either happening all at once, or one after another. This suggests that caregivers have to navigate a sense of uncertainty and unpredictability, described as an *"unknown quantity" (IP 4, L 28)*. This makes planning and having a sense of control very difficult and could be deemed as,

> *"... just lumbering from one thing to another sometimes, a bit chaotic." (IP 7, L 394-396).*

This can be exacerbated when the caregiver is required to manage a multitude of events and activities, requiring the need to balance several events.

> *"Because, it's no easy task, they're both in their mid-eighties, dads got his set of problems, mum's got her set of problems. On top of that, they're also grieving for their daughter, so there's a huge thing going on. And then, also, my twin sister, she's got a heart problem, so she's undergoing tests at the moment, so we've got multi things going on here." (IP 8, L 146-153).*

Unexpected or unplanned events further minimises the perceived control that caregivers may expect to have.

> *"My sister also, in August 2013, she had major heart surgery, she had a sudden illness ... That's the first time we had any respite from mum, social services said, you can't look after your sister, and your mum, so they arranged a two-week respite in [Village] ... so I don't really know how I juggled round with that." (IP 7, L 249-250; 251-254; 257-258).*

Above, the participant is uncertain how they managed to 'juggle' all the different aspect going on, at that moment, in their life. This suggests that, at the time, they seem to manage and possibly only on reflection, realise the difficulties that they have faced. Unexpected development may invariably cause delays in accessing and seeking support,

> *"We were starting to look into the business of going to day centres ... that is being investigated by the Admiral Nurses, but we've had to put it on the back burner just lately, because of illness and bereavement in the family." (IP 5, L 685-686; 692-695).*

One participant described their emotional state, when they felt that things had become too much. A series of bereavements made it difficult to manage and cope at that time and required some support through the GP,

> *"When [Husband] was diagnosed, in 12 months I lost nine close friends and family, and I just had enough ... I didn't know where to go, or what to do. Again, I went to the same GP, and I've actually, since then, been on a very low dose antidepressant, and it just keeps me like that." (IP 4, L 259-261; 263-266).*

Commitments that occur outside of their role of providing care can cause unexpected setbacks for participants.

Overall, the different commitments that caregivers are required to 'juggle' are unremitting; with unexpected events and set-backs that occur to further encumber their positions as primary care providers. This can impact on their own health and psychological wellbeing, which may impact on their ability to deliver care. It is interesting to note, work commitments mostly related to ACCs, rather than spousal caregivers.

4.4.5.2. Reality gap

This code relates to caregivers trying to find a ‘happy medium’ between, any desired and planned expectations, compared to their new and current reality as a caregiver. For nine of the participants (82%), the role of caregiver would not have been chosen, which may evoke feelings of anger, resentment, as well as a sense of feeling cheated.

> *“And, basically, as I say, I felt cheated, I felt angry, upset, you name it, I went through the emotions.” (IP 4, L 278-280).*

> *“I did resent her at times, you know, if I’m honest.” (IP 9, L 237-238).*

Different losses were described by participants, which they have encountered due to their CR becoming ill.

> “*Because, we had planned for retirement, we’d got a time share thing, that we were going to go here, there, and everywhere. Of course, all of that was taken away from us ... That goes back to where I feel cheated, you know what I mean, my life, my retirement, well ours, I should say, has been taken away from us.” (IP 4, L 280-283; 671-673).*

> *“... we should be, you know, enjoying a nice period of our life, doing things, having trips out, but you’re frightened all the time that something is going to happen, that she’s going to flip and cause a scene in the open air, or something like that.” (IP 5, L 655-660).*

This participant uses the phrase ‘frightened’, suggesting that they are worried or concerned to act in case something happens.

Spousal caregivers were more likely to highlight the loss of their partner and intimate companion.

> *"I've lost [Husband], the husband that I knew." (IP 4, L 288-289).*

> *"That's it, it's a weird situation, instead of a marriage, in [Wife's] mind, it's just been a friendship, and she says, I couldn't manage without you, you've been a good friend." (IP 5, L 521-524).*

One participant mentioned having gone through a "grieving process" (IP 4, L 288), and has processed the loss of the relationship with their spouse by having,

> *"... removed myself from being his wife, and I am just his full-time carer, because all that side of the relationship has gone." (IP 4, L 290-292).*

Further to this, some spousal caregivers have had to make additional adjustments to their new circumstances, which they have described as difficult; especially when they have had to exchange something familiar and comfortable for something new and unknown.

> *"When you've slept together for years, then you've got to split up, because I wasn't getting any sleep ... That was a big step as well, you know, having slept in the same room for years, and then you've got to split up." (IP 6, L 34-35; 41-43).*

The loss of conversation, especially with someone that was deemed a confidant, was expressed as another deprivation.

> *"I mean, we don't tend to have conversations now, because he doesn't understand anything ... We have to deal with all that, and you've got nobody to talk anything through with." (IP 2, L 656-658; 662-663).*

Throughout the interviews, some participants also expressed a sense of having to 'give up' certain tasks and leisure pursuits, which they enjoyed, in order to continue to look after their loved one, especially as the condition progressed.

> *"Well, it's been a big problem for me, because I've been very active, physically, in my life, I was a professional footballer for 20 years ... So, there's a big gap, and I was involved, after I'd finished playing football, I was involved in organising running as well, I organised the [Town] 10k run for ten years, I actually set it up. And, prior to that, I used to organise the ten-mile run over at [Town] for my trade union. These were big events that needed a lot of input, so I had to stop doing that." (IP 6, L 80-82; 86-92).*

> *"... we might still have a car ... He used to love going out in the car with the dog, he really did. Things change, I'm afraid." (IP 10, L 139; 146-147).*

Having to alter their pursuits were more difficult for some to accept and they expressed a sense of intrusion in their lives.

> *"My life has changed completely, I can't do anything, unless I have arranged for a carer to be here. My mother cannot be left for one moment ... It's just her needing constant reassurance. So, your life isn't your own." (IP 11, L 34-37; 199-200).*

> *"Because, towards the end of her living here, I was beginning to resent it, and I was beginning to feel that it was completely encroaching on my life." (IP 9, L 1492-1495).*

Participants shared their sense of a perceived gap between the reality that they envisioned for their current and future life. The losses described in terms of expected outcomes, where highly emotive and negative, the majority feeling cheated and *"aggrieved" (P 4, L 675)*. Of note, spousal caregivers highlighted lifespan changes, i.e. retirement plans, more so than adult child caregivers.

4.4.5.3. Torn loyalties

Of the participants interviewed, seven (64%) indicated that, at times their loyalties were torn between different commitments. Managing and maintaining their own demands, whilst balancing the needs of others, especially in relation to those who exact a paternal or spousal pressure.

> *"So, yes, it's being pulled from all different directions, because your own children still put demands on you, in some way or other, and then you feel sandwiched in the middle." (IP 9, L 925-928).*

As this participant describes, this enacts a feeling of being 'caught in the middle'. This was also expressed by another participant,

> *"I've also got a special needs daughter, who needs help, and it sometimes becomes a constant battle who wins, and it's never me ... in the middle, and I'm the one who is last in everything. If I'm not here, it's fine, it's this three-syndrome." (IP 2, L 16-19; 24-26).*

They describe having 'lost the battle', which may suggest that their sense of worth is worn down as the condition progresses, potentially leading to a point where they may experience distress. As the following participant states,

> *"I felt tied, in my loyalty between her, and my loyalty to my husband. Because, I wanted to scream and shout, and I didn't know who I could scream and shout at." (IP 9, L 620-623).*

This was expressed as a need *"to keep peace at any price with everybody" (IP 9, L 685-686)*, at the expense that *"I wasn't thinking about myself" (IP 9, L 686-687)*. Being *"piggy in the middle" (IP 9, L 214)* between the CR and other family members, caused significant difficulties for one caregiver who expressed concerns that,

> *"I'm going to have to go onto antidepressants, or something, because I just felt really low, because I felt like I was juggling 100 things." (IP 9, L 1209-1211).*

The experiences related by the interview participants were, that they found themselves central to maintaining the equilibrium between their CR, their own demands and commitments, and other dependents. Some expressed the difficulties they encountered, due to causing divided loyalties, as the CR would take priority over other obligations for the majority of the time.

Overall, this theme evokes a sense that caregivers are caught between their sense of obligation to provide care, to their loved one, and a duty to their own self-fulfilments and wellbeing. They are also physically caught between a struggle to maintain given commitments; between employed work, family and other dependents, as well as leisure and social activities with friends. Unable to achieve this perceived balance, between their current and desired realities can create distress. Caregivers struggling to adapt and adjust to these changes will find it difficult to manage the increasing strain on their resources.

4.4.6. Unsustainability

The theme of unsustainability refers to caregivers being unable to maintain their increasing role in providing care with limited resources. The majority expressed the realisation that caregiving cannot be maintained or continued indefinitely; especially given the impact on their psychological wellbeing and the physical strain experienced by the participants.

4.4.6.1. Acknowledgment of fallibility

Ten of the eleven participants (91%) interviewed, acknowledged their fallibility that at some point in their caregiving career, they may not be able to continue in their current state or trajectory, without compromising their own health or other loved ones.

> *"Well, I've got no energy at all. It's more mental actually because, I've lost quite a bit of weight doing it, actually, with all the stress, and worrying, and mithering." (IP 1, L 284-287).*

> *"I get very, very tired, which is why my brother and I pay for extra care, because I fully recognise I can't provide a good quality of care for my mum, if I'm exhausted. So, I have to accept there are things that I can no longer do for her, at the moment." (IP 11, L 204-208).*

> *"... there's going to come a time where I'm going to need more than just two weeks a year, even if it's only three or four days." (IP 4, L 833-835).*

> *"So, the best thing is for someone to allow me to have proper respite care. Because, eventually, what will happen is that, the carer won't be able to cope, they won't." (IP 8, L 338-341).*

Some expressed their commitment to continue to provide what they are able.

> *"I'm not saying that I'm going to be able to do it next week, next month, next year, I don't know, you know, my feeling, personally, is that I will keep going as long as I can." (IP 3, L 157-161).*

A few mentioned that their age is a factor that also needs to be considered.

> *"I manage okay, I manage okay. I'm not getting any younger either." (IP 3, L 635-636).*

> *"But, there comes a time when you have to think. Well, I'm not getting any younger." (IP 9, L 1466-1467).*

As the condition progresses and deteriorates, participants recognised that their abilities to maintain and continue their role will also change. Some may not be able to maintain their current input and require further support and adaptation, in order to continue to meet the growing demands of their CR. This recognition that they are not infallible does not prevent them from expressing a sense of feeling guilty or being selfish when they take time for themselves.

> *"I need some me time, which may sound selfish." (IP 9, L1468-1469).*

> *"I have to keep telling myself this, you know, enough is enough, you can only do what you can do. And then, that's easier said than done, and ten minutes later you think, oh, I feel a bit guilty, because I haven't been." (IP 1, L 477-481).*

This participant describes this as a *"double-edged sword, you can't do right for bloody wrong" (IP 1, L 482-483)*. This conveys the continual discord that caregivers must face.

Some participants have managed to overcome their feelings of guilt, in order to provide a better quality of care for their CR.

> *"One of the biggest things, that I've had to overcome I think is the guilt, that I'm not the one with Alzheimer's, he is. And ... that I must not feel guilty, but I must have some me time, to be able to cope with him long term." (IP 4, L 1181-1184; 1186-1188).*

> *"But, I recognise that I have to have my own time, and it used to be I felt very guilty, but I don't know, because I know that, if I don't have that break time, then I'm no good to anybody ... Just really realising that, that was not really doing anybody*

> *any good, if I didn't take the time out, then my temper was short. I was short tempered, then I felt guilty, because I was short tempered. So, it was much better at first to feel guilty that I'd paid for somebody to sit with my mother and know that she's safe, than it was to think, I shouldn't have said that to her, I shouldn't have spoken to her like that, I should have spent more time with her. It was a much better guilt, having somebody else give me time out." (IP 11, L 227-231; 236-245).*

This participant transposes her guilt in order to actively engage with it as a positive adaptive mode to maintain her role as caregiver.

> *"... it's not that one is a martyr or anything like that. So, that's a blessing from that point of view but, nevertheless, one does need time out, and quality time." (IP 8, L 109-112).*

> *"It wasn't helping me, and I actually needed time away from it, because sometimes they say you need to go there and mix with other carers, I needed time away from that, I needed a break from the caring ... thing altogether." (IP 7, L 165-169).*

Most participants expressed a need for *"time out" (IP 8, L 111)*, however, they acknowledged that this needed to be of a certain standard, *"quality time" (IP 8, L 112)*, in order to make it worthwhile for them and to meet their own needs and requirements. Most expressed a need to have a complete break.

> *"I actually needed time away from it ... I needed a break from the caring ... thing altogether." (IP 7, L 165-166; 168-169).*

> *"I just want to go away and have a complete break." (IP 1, L 516-517).*

> *"... every one of us says that it would be nice to have that time, when you're totally on your own." (IP 2, L 395-397).*

Most participants acknowledge that their ability to continue and maintain the level of care and input that they currently provide is not limitless, as they are essentially ‘only human’; although, they admit feeling guilty for needing a rest and a break from providing care. They also understood their own need to have quality time away from their caring role, otherwise it will become detrimental to both them and their CR. A greater need was expressed for time to themselves, as the CR proceeds into the later stages and the condition progresses.

4.4.6.2. Maintaining role

In order to continue in their role as a primary care provider, all participants (100%) related the practical and other supports they have used, in order to maintain their current position. Many spoke about getting outside assistance, such as domestic help, to alleviate some of the day-to-day pressures of maintaining a household. As expressed by this participant, a concept which would never have been considered before:

> *“And, I’ve actually done something in the last fortnight, which I never ever thought I’d do, I’ve employed a cleaner, to take a bit of pressure off me ... I’ve employed a window cleaner outside, which I’ve never ever done before.” (IP 4, L 141-144; 156-157).*
>
> *“Perhaps, having a cleaner in at some time, might be reasonable.” (IP 6, L 546-547).*
>
> *“We have got someone who will come and do an hour, after he’s done his work. And, he does the general ... he weeds, you know.” (IP 10, L 364-366).*

Some have used assistive technologies, in order to manage care tasks.

> *"I've tried to get as many gadgets, or whatever you want to call it, the occupational health have brought me a stool to put in the shower, because he can't stand up in there." (IP 4, L 179-182).*

One participant mentioned that they had to physically remove themselves on occasion, in order to have time away from their CR and the care environment, as a means of preventing the build-up of frustration and potential resentment.

> *"I mean, you know, when I say to you, I tried to take the line of least resistance, there were times when I could have screamed into a pillow, and probably did on a few occasions. Or, [Husband] said, come on, I'm taking you out, let's just go and have a drink, or something, because I can see you're getting all wound up. A couple of times, we went away for the weekend." (IP 9, L 168-175).*

For some participants, the capacity of the CR to carry out tasks and maintain some independence was felt to be important. It also allowed them to *"escape at times" (IP 2, L 134)* if they felt confident that their loved one could look after themselves for a short period of time, allowing the caregiver to see to their own needs.

> *"I've still got a social life, I can leave my mother for periods of time, and I'm quite confident that she's not going to come to any harm." (IP 3, L 106-108).*

> *"At the moment, I can leave him on his own, because I know he won't … other than falling, he won't go anywhere, or do anything, or touch anything, you know what I mean." (IP 4, L 330-333).*

Although, realising that a point will come where *"maybe, in time, I won't be able to, without somebody sitting with him" (IP 10, L 107-108).*

Several participants made use of paid care support to relieve some of the pressures on them and to reduce the potential risk of leaving the CR on their own.

> *"... we looked after her here, we started getting carers in at a later date." (IP 7, lines 57-58).*

> *"And, when she was here, we had a carer coming in on the Thursday night, to make sure everything was okay, because that was at the point where I was finding weird things in the toaster, and thought that we might end up with the house on fire." (IP 9, L 408-413).*

One participant utilised paid care support to free up their time, thus, allowing them to continue with other tasks and manage additional commitments.

> *"I've organised some light early evening care, so they do dad's private ablutions, and put him in his PJs. So, that actually releases me, whilst I can do it when I'm here, but at least I can be doing my emails, or make my phone calls, or whatever it is I want to do, so that helps." (IP 8, L 192-198).*

Along with the realisation that care cannot be maintained indefinitely, many questioned how long they would be able to continue in their role as care provider.

> *"I don't know whether it would have been possible to have known how it was likely to progress, and how it was likely to affect me, and the timescale, how much time she's got before it becomes impossible for me to look after her." (IP 6, L 688-692).*

> *"Yes. It was hard, it felt like all your life had, sort of, disappeared into doing this one thing all the time, and you're trying to work out how you were going to do it, and how much longer you could do it for." (IP 7, L 285-288).*

This participant used the description that their *"life had, sort of, disappeared" (IP 7, L 285-286)*, bringing to mind an image of a 'black hole'. This possibly suggests that their life is on hold and fairly limited at the moment.

This code demonstrates that several mechanisms are utilised in order to maintain the role as primary care provider. Practical domestic support was the main area that caregivers discussed and what they would find the most useful to help support their position. Having a break and emotional detachment also supported participants to maintain their roles.

Overall, this theme recognises that providing care to an PwD is not a sustainable recourse; a never-ending demand on the caregiver. More importantly, caregivers acknowledge that they are fallible and question their own ability and resources to maintain their role. Most participants indicated an obligation to continue to provide care, for as long as they were able, which was reflected as unsustainable. Caregivers have a finite resource and capacity to provide care, on this descending trajectory and are aware of their own caregiving limitations; without factoring in their own physical and mental wellbeing.

4.4.7. Adaptation, adjustment and effects on care

This theme encompasses the adaptation and adjustment that caregivers experience, providing care to a PwD. Interviewees mentioned the gradual change and deterioration of their CR, outlined their perceived responsibilities, obligations and personal misgivings of their ability to carry out their caregiving role.

4.4.7.1. Metamorphoses of care recipient

All participants interviewed (100%) indicated in varying degrees the marked transformation their CR underwent. This included several facets that encompasses the CR, the caregiver, their relationship between them; as well as social and environmental factors. Most participants recall how their loved one was, prior to their deterioration, and find it difficult to equate to the same person, as the disease progresses.

> *"I remember what she was like, very smart, always had lovely clothes, always well turned out, always had her hair done. And, she'd gone from that to being, just nothing like herself, you know, hair all over the place, not cleaning her teeth, dinner down her top." (IP 9, L 708-713).*

> *"But, I look back, and I think what my mum was, then it's very disappointing, and you think, God, why did that happen." (IP 3, L 212-214).*

Another aspect that is mentioned, is the lack of communication and loss of understanding, which appear to be one of the most important aspects that participants specified.

> *"I think, the last two years have been the worst, and now it's extremely difficult, because of him not understanding anything." (IP 2, L 72-74).*

> *"At the moment, I just can't have a conversation with her at all. I mean, she does have, well, she does recognise me, obviously, but you can't hold a conversation with her at all." (IP 6, L 55-558).*

> *"So, when you realise that you're losing the person, that you could sit and chat to, and discuss things with." (IP 11, L 168-170).*

A further difficulty highlighted, appears to be caregivers providing personal care to their loved one if they develop incontinence.

> *"I suppose, incontinence was a big ... well, gradually, I mean, it gradually developed the incontinence did, roughly at the same time as you lose the ability to have a conversation with her, you know." (IP 6, L 227-230).*

> *"And, I think, it sounds a bit crude really, but one of the things that really hit home with me is, I had to help my mum wash herself one day, because she'd made a mess in the toilet and I had to wash her down." (IP 7, L 14-17).*

This participant likens having to wash their CR as *"just like doing a baby" (IP 7, L 19)* or that it is similar to looking after a child, *"they go childlike" (IP 7, L 11)*.

Other difficulties that some participant found particularly difficult, was incidences of CRs walking out of the home or a tendency to hoard items and objects.

> *"... we had episodes of her wanting to walk out the bungalow, and there was nothing my dad could do, because he couldn't chase after." (IP 1, L 72-74).*

> *"There just isn't any real pattern to anything, other than this hoarding." (IP 5, L 601-602).*

Some participants found that they had to prompt their loved one to maintain their standards of hygiene or they would become unkempt.

> *"Well, I have to chivvy him to have a shave, I have to chivvy him to have a bath, and to change his clothes." (IP 10, L 42-43).*

> *"... she didn't want to wash, wouldn't change her clothes ... wasn't capable of looking after herself in the last ... she lived in my mum's house for a year, before we moved her in with us, and because it was becoming unkempt." (IP 9, L 85-86; 1526-1529).*

The unpredictability of behaviours and gradual deterioration is also mentioned and that, at times, the CR can be living in a different era or was content in their 'own world'.

> *"... she seemed to be happy in her own little world, and not really that aware." (IP 9, L 63-64).*

> *"It's just that her mind has completely stopped off at a certain period in time, and that's 50 years ago." (IP 5, L 572-573).*

It appears that these participants are mere witnesses to the metamorphosis of their CR, brought about due to their deteriorating condition. Even though it can be argued that the PwD does not solely go through a transformation process; the process of adaptation can be said to inflict change on the caregiver, who may undergo their own alterations.

4.4.7.2. Learning curve

This code relates to the aspects of learning that are developed during caregiving and the skills acquired through experience. Nine participants (82%) suggest that this is not a quick or speedy process; rather it proceeds moderately over time and is dependent on the needs to be met at that particular time.

> *"It's not a sudden adjustment, it isn't something that, one day everything is fine, one day you totally do whatever you want whenever you want, to having the responsibility of being a carer, it doesn't happen in 24 hours ... So, it isn't a question of, I've suddenly got to alter things, you alter things as and when needs be, over the progression of the illness." (IP 3, L 63-67; 68-71).*

> *"She would change, as well, you'd think you'd got a pattern for a couple of months, and then she'd change, and something else might disappear." (IP 7, L 398-400).*

As this participant suggests, *"it's constant adapting" (IP 7, L 408)*; which indicates the uncertainty and unpredictability that is known when caring for a PwD. Especially, as they relate above, it fluctuates and changes. This might add to frustrations and difficulties when trying to manage the situation. A few participants mention that they have developed certain strategies or techniques to support them with managing the behaviour of the CR, in order to *"get round" (IP 9, L 107-108)* providing the necessary care tasks.

> *"We use a little device ... I don't know whether you'd call them tricks or not ... Techniques, if that's what you want to call them." (IP 3, L 304; 306-307; 311).*

This is most likely due to the fact that the majority are primary caregivers managing on their own for the most part.

> *"I manage on my own. I mean, after a time, you do develop techniques to deal with it." (IP 6, L 51-52).*

Participants reiterated that *"you learn the hard way" (IP 3, L 312-113)*, suggesting that a lot of difficulties could have been avoided if they had known these *"tricks" (IP 3, L 307)* beforehand.

> *"It's stupid, it's just knowing what to do, and these little clues, if you like, as to how to manage it. That could all have been avoided, if I'd have just put that there. So, you know, it is a learning curve, but a learning curve I hope I never have to experience again." (IP 4, L 1038-1043).*

As this participant states, it is a 'learning curve', which they do not wish to repeat.

Other ways that participants have found, is to establish a fixed routine to make their roles easier to manage, as reported by the following participant.

> *"When I get her up in the morning, I follow the same procedure every day, and give her breakfast, and what have you." (IP 6, L 156-158).*

The *"practical things" (IP 6, L 154)* are easier to manage, than perhaps the emotional or behavioural factors that accompany the changes. Alongside managing the practical aspects, are the use of assistive technologies, e.g. 'gadgets' and use of practical equipment.

The use of practical equipment and gadgets are also part of the strategies developed by the participants.

> *"... putting things for your mum in clear canisters, putting what it is on there, a name, and perhaps putting a picture of your mum on it. So, we were doing things like that, we put teabags in clear canisters, and milk, and tried labelling things, put mum on it." (IP 7, lines 334-349).*
>
> *"... she'd locked us out of the house loads of times, we were locked out lots ... in the end we had a key safe put out the back, so that if we did get locked out, we could get back in again." (IP 9, L 287-88; 294-296).*
>
> *"... he fell again in the bedroom, I went and got a bottle for him, so he didn't have to come out of the bedroom ... touch wood, since I've used the bottle, we've had none of them episodes." (IP 4, L 609-611; 642-644).*
>
> *"As I say, when we first moved here, we had two single beds in here, but it wasn't practical. I put that up as well, that wardrobe, it needed a sliding door, so we could get it in." (IP 6, L 463-466).*

Most of these techniques or strategies appear to develop after a difficulty had occurred and a solution is required. One participant uses the phrase *"touch wood" (IP 4, L 642-643)*, which suggests that they are trying to prevent further 'bad luck'. Another participant mentions having *"to step into their world" (IP 7, L337-338)* as a way of thinking, to support the adjustment to the changes brought about by the illness. This suggests that participants may require a need to be more open minded and to try 'new ways of working' with their CR, and also perhaps, needing to think 'outside the box'. This may mean trying new strategies that takes them out of their 'comfort zone', as this participate relates:

> *"I can recall going to the one session, that the Admiral Nurses did ... she was saying about how soothing touch and that sort of thing was. I can remember thinking at the time, this is a bit airy fairy sort of stuff, but it's true. You see, now, there are times my mum will sit down next to me and just rub my leg, and it seems to give her comfort." (IP 3, L 740-741; 743-749).*

The majority of the participants suggest that it is an *"ongoing situation" (IP 4, 201)*. Part of their adjustment and adaptation is learning to compromise, in order to fit in with the CR as much as possible, as they undergo changes. Some have even adopted a trial-and-error method, to see what works best in a given situation.

> *"We did go to Singing in the Brain ... I think, what we will do is, we will try to cut out the beginning bit, because it was too long, it's two hours, it's much too long for him ... Cut out the tea and biscuits bit, and just go for the singing bit. I'll try a few times, and if it really gets too much, then we will have to stop." (IP 2, L 374; 375-378; 382-384).*

Most were concerned about respecting and preserving the dignity of their loved one and were careful of their own actions, so as not to demean or humiliate them further.

> *"I used to have to go in at night, when she'd gone to bed, which was often difficult, because she often went to bed later than we did ... So, I'd have to sneak her clothes out, because if I told her they were dirty she got quite cross, and I didn't really want to humiliate her, to be honest." (IP 9, L 86-89; 91-94).*

> *"Because, going out for a meal with [Husband] now, is too much hard work ... I'll order for him, and then he'll say, what have I ordered, and I'm sure people think ... but, I don't like telling everybody, it's alright, he's got Alzheimer's, it's a bit demeaning, isn't it, so I try to be as discreet as I can." (IP 4, L 765-766; 769-773).*

This participant uses the phrase ‘discreet’, as if the diagnosis needs to be hidden, almost in a shameful way. This suggests that dementia in some respects continues to be ‘taboo’.

These experiences represent the ‘shallow learning curve’ that dementia caregivers undertake unintentionally, in order to adapt to the gradual changing circumstances of a progressive condition. The majority of participants expressed a sense of learning using these ‘trial-and-error’ methods, using compromise where necessary or developing solutions as needs arise, through ‘problem-solving’ mechanisms. Establishing set routines and effective strategies also appears to aid them in their caregiving tasks.

4.4.7.3. Responsibility for superior care

Nine interviewees (82%) expressed a moral obligation to provide a high standard of care to their CR. Otherwise, it was perceived by them as their duty to act on behalf of their loved one, to ensure that they are given the highest quality of care available, if they were unable to deliver it themselves.

> *“I did one day, put my arm round my mum, and said, look, you know, you’ve looked after me all my life, it’s time I looked after you. That took some saying, believe me, but, yes. So, I stand by that sentence, and I intend to.” (IP 1, L 712-716).*
>
> *“I’ve got a responsibility to my mum, and I’ll fulfil it as long as I can, it’s as simple as that. We’re quite close ... The alternative is probably not so good for my mum, I’m sure these care homes do sterling work, but I don’t think she’d get the same sort of treatment and time that I can provide for her at the moment.” (IP 3, L 151-153; 161-165).*

The majority who felt the strongest sense of moral obligation were child adult caregivers, who expressed a strong sense of duty towards their CR.

> *"I just think you feel this obligation with a relative." (IP 9, 1445-1446).*

> *"You suddenly feel the person that's looked after you, from a small child, you've now got to look after them." (IP 7, L 6-8).*

For spousal caregivers, they tended to use the phrase "*conscience*" *(P 4, L 489; P 6, L 1152)* to denote their moral commitment to their partner.

> *"Yes. It's not easy, as I say, the biggest problem is that you have a conscience as well, you've got to do this, you've got to get her right ... I mean, how long I can ... well, as long as I'm physically capable of doing it." (IP 6, L 488-490; 738-740).*

> *"I suppose, they're going to rely on me to provide the service for her. Fortunately, as I say, I've kept myself physically, I wouldn't say extremely fit, but very fit over the years, and consequently I'm able to, you know, look after her physically." (IP 6, L 737-744).*

Some participants indicated that, although they felt responsibility for ensuring the safety and wellbeing of their CR, they wanted to maintain as much of their loved one's independence and dignity.

> *"... what I didn't want to do, was completely, you know, deskill her in everything." (IP 9, L 124-126).*

> *"But, I do everything I can for him. I try to make him do things himself, I'm not taking him over, but I have to be aware of everything he's doing." (IP 4, L 129-131).*

This suggests that caregivers must negotiate a fine balance of ensuring the person is safe, without falling into a scenario where they are overprotective, *"it was just a case of, not molly coddling him" (IP 4, 70-71).* To manage the care of their loved one, some participants used paid care support. Those that used this facility related their experience as varied, and voiced their concerns around the quality of care provided by external agencies and care services. Some were more amenable, as long as the care tasks were being done that was set out; as this participates states,

> *"I went along with the flow with this care firm, and the package they put together I was quite happy about, as long as they did their job, and what they were supposed to be doing ... I still want, obviously, her cared for as best they can." (IP 1, L 400-403; 278-279).*

Others felt more strongly about ensuring *"good quality care" (IP 11, L 89)* was provided to their CR.

> *"Yes, you can get care, but from what I've seen, and rejected, it isn't any care that I would want to receive. And, I think care is very much a misnomer, and not allowing the person dignity, and that is so important." (IP 11, L 90-94).*

They use the phrase *"care is very much a misnomer" (IP 11, L 92-93)*, which strongly indicates that they feel the concept of providing care is currently inaccurately understood, and therefore, supplied with little thought of *"dignity" (IP 11, L 96).*

> *"I think, if you have one good carer, that can only come for two hours, that is far, far more beneficial, than one poor carer that can come for four hours. Because, that poor carer can do far more harm, agitation, upset, and then it takes so long to settle everyone back down again, into a good solid routine, where they feel safe." (IP 11, L 104-110).*

They relate that this,

> *"... actually costs us another £600 a week, over and above what we get from care", so my brother and I find that money. And that allows me to have a little bit of life for myself." (IP 11, L 111-115).*

This appears to ensure that some happy medium is reached that satisfies both parties and *"it gives me confidence that I know that she's getting the best that I can possibly do for her" (IP 11, L 127-128).*

Overall, participants related that they felt responsible to ensure that a high standard of care for their loved one is provided. If not, the majority held themselves accountable if this expectation for superior care was not met. Even, as one participant expressed, paying more to ensure *"quality care" (IP 11, L 89)* is provided that allows the person their *"dignity" (IP 11, L 385).*

4.4.7.4. Personal misgivings

This code reflects the feeling of doubt that participants have emphasised throughout the interviews, about the consequences of not providing a superior quality of care to their CR. Nine of the interviewees (82%) stated that, they wish to do the best for their loved ones in terms of providing good quality care. Some have appraised their own performance in achieving this outcome.

> *"So, I think, I don't know, it's a very individual thing, whether you feel you can do it or not. And, I felt I could do it, and I think I did a pretty good job of it." (IP 9, L 1463-1465).*

> *"It gives me confidence that I know that she's getting the best that I can possibly do for her." (IP 11, L 127-128).*

Participants felt for the most part, that "*I do what I think is the right thing*" (IP 3, L 157), and as one participant states,

> *"I feel like sometimes, you know, I can't do enough, but I can only do so much." (IP1, L 116-117).*

There were a few participants who voiced their own lack of confidence, using phrases such as *"it's not your fault, is it" (IP 3, L 241).* This suggests that they are seeking an absolution in case they had got it wrong.

> *"… a lot of it has just been off the cuff, we've done what we've thought is right, and if it's not right, you know, nobody can shoot us down in flames, because we've done what we thought was right." (IP 1, L 326-330).*

Their use of the phrase *"nobody can shoot us down in flames because we've done what we thought was right" (IP 1, L 328-330)* is a powerful metaphor to emphasise this idea of survival amidst all the struggles and difficulties that they are facing. Some have reflected on their choice of becoming a caregiver,

> *"But, it is a big decision to make, and I don't think you've got any idea how big it is, until you're in it. That's the other issue, you think you're doing the right thing at the time and, in hindsight, it would have been much better for [Aunt] to go into some sort of sheltered accommodation. My relationship with her would have been better." (IP 9, L 1482-1489).*

This participant had noticed a shift in their perception and attitude, now that they have shared some of the care.

> "*I think that's the other thing since she's not been here, I'm much keener to go and visit her, and sit and chat with her, and have a laugh with her." (IP 9, L 1489-1492).*

For most, it interlinks with a sense of feeling guilty, questioning whether they are making the right choices for their loved one; without appearing to be motivated by selfish reasons. Some participants appear to require some reassurance to lessen feelings of guilt, "*I shouldn't feel guilty about that because, if I can't do it, I can't do it" (IP 1, L 749-750)*, and that they are cared for as best as they can be.

> *"I do feel she's well cared for, yes. But, if there is any guilt, it's just because I'm worried that maybe she wishes she was still back here, do you know what I mean?" (IP 9, L 787-790).*

> *"... although we felt guilty about doing it, it seemed like the best thing, because she was just going to have 24-hour care, she will be in company all day with other people, other residents and stuff." (IP 7, L 62-65).*

The use of the phrase *"it seemed like the best thing" (IP 7, L 62-63)*, suggests a need to justify actions and decisions that were made. This possibly indicates that they are trying to preclude a judgement on themselves. One participant expressed that their main concern related to ensuring that their CR is looked after in the best way possible, by providing them with as much pleasure and enjoyment as they are able.

> *"Making life better for [Husband] ... If I can make his life any easier, or more pleasurable ... whatever I can do for him. Whatever he wants ... whatever he wants, if it's within my power. I'm not saying it's a bottomless pit, but if he wants it, he can have it ... It's not saying I'm trying to buy a solution, because there isn't one, but I'm*

> *trying to make his life as comfortable, and as enjoyable as I can, pleasurable, if that's the right word." (IP 4, L 485; 496-497; 503-504; 508-510; 527-530).*

Most participants expressed a sense of self-doubt about providing the best possible care in their roles as primary caregivers. The majority of participants felt that they have acted in the best interests of their loved ones and continue to do so; most had reservations of doing or having done the right thing. As one participant suggested, most decisions were made without guidance and had *"been off the cuff" (IP 1, L 327).* This potentially could have exacerbated the feelings of self-doubt.

Overall, this theme of 'adaptation, adjustment and effects on care' highlights the changes that caregivers experience and undergo, in order to become familiar to their evolving situation. With the evolving decline of the CR's function, over time, caregivers have had to adapt to constant changes and adjust appropriately to their loved ones new presentations. This is paralleled by a strong sense of obligation to provide the highest quality of care, for which caregivers personally appraise and criticise their own performance.

4.4.8. Coping strategies

This theme reflects the range of different coping strategies that caregivers have used to support themselves when looking after an individual with dementia. Six codes have been interpreted from the data, which contributed to this theme. They generally refer to the specific coping mechanisms that individuals have employed to reduce their level of stress; and may be classed as useful or maladaptive.

4.4.8.1. Removing self

Nine participants (82%) emphasised the use of removing themselves, either physically or emotionally from the care environment. This indicates a method of coping that uses the idea of distancing oneself from the source of distress or conflict, in order to cope and manage the situation better. The majority of participants describe un-connecting from their environment through physical absence, by taking themselves away, in order to have respite. This was mainly described through use of leisure pursuits.

> *"Well, I have one two-hour slot a fortnight, and I go to a craft group." (IP 2, L 49-50).*
>
> *"I go to Pilates, one hour a week on a Wednesday ... I leave here at ten to two, and I'm back here at ten to four, four o'clock, and that's basically my me time, that's all." (IP 4, L 719-720; 725-727).*
>
> *"I do just get one evening out, I play bridge on a Tuesday night, and that is the only time I get out and have any time to myself." (IP 5, L 72-75).*
>
> *"Well, I walk the dog, and I like to watch soaps in the evening ... About three times a week ... Plus, my shopping ... perhaps, once a fortnight." (IP 10, L 59-60; 92; 96; 100-101).*
>
> *"Yes, I like playing badminton." (IP 8, L 181).*
>
> *"I might go and have a walk up the lane, or something, for half an hour, nothing outrageous." (IP 3, L 96-98).*

From these excerpts, the majority describe limited abilities to go out and enjoy hobbies or leisure pursuits, and this may become increasingly difficult as the condition of their CR progresses. Some participants expressed that they have readjusted their routine, in order to have that time away, even if it requires staying home, making time to pursue their interests and hobbies were possible.

> *"Having my own bedroom, it's like my sanctuary. I go in, I shut the door, that's me time, watch what I want on the television, do what I want, have a shower, or whatever, that's the one thing." (IP 4, L 713-716).*

> *"I bury my head in books. I've never got a book far away from me. I always do my puzzles, though [Husband] does his puzzles too, we're not allowed to do each other's puzzle. And, I do embroidery and sewing, and craft. If I didn't have those, I think I would probably go mad. I think, you know, as long as I can always read, I will always bury myself in a book." (IP 2, L 163-170).*

A few interviewees used the phrase *"me time" (IP 4, L 730)*, possibly in order to differentiate their time from that of their care tasks and time spent with their CR. It is suggestive of being precious and the need for it to be protected, *"that is me time, nothing gets in the way of that" (IP 2, L 5-51)*. On participant mentioned the value that they found in accessing her church as a form of respite, accessing a support network and having some semblance of a social life.

> *"And, I go to church, I find that's my salvation ... And, there's things going on there ... So, yes, I've got a bit of social life there, so I do look forward to those things." (IP 10, L 68-69; 81; 86-88).*

Some participants have also described a sense of removing themselves emotionally from the situation; indicating that they create a state of remoteness in order to manage their levels of distress better.

> *"But, it's to try and, as I say, avoid the emotional side, and to think of ways of coping with it when it does get too much and." (IP 4, L 341-342).*

> *"Well, I suppose, you get angry at times, not that I ever show it, because I tend to keep my emotions to myself." (IP 2, L 150-152).*

> *"To hear someone in pain, and not to become emotionally involved, and to remain detached, but try and create some sort of empathy, is hard going, day in, day out, that I find, it is hard going." (IP 8, L 173-176).*

One participant used the phrase of needing *"to learn to almost divorce yourself from that person" (IP 11, Lines 370-371)*, suggesting this emotional separation allows the caregiver to manage better when looking after someone that you have *"actually lost" (IP 11, L 372).* This may support the grieving process in the longer term.

Participants have found specific methods that allow them to distance themselves from their loved one and the care environment, in order to reduce the stress associated with providing care.

4.4.8.2. Having an outlet

This code relates to caregivers exhibiting the adaptive use of external social resources, in order to cope better with a stressful and demanding situation. Eight participants (73%) utilised family support or their social networks as a means of relieving any frustrations or worries.

> *"But, I speak to my dad's sister quite a lot about it all, and she said, you know, you want to remember, look after yourself, never mind, you've got your own family and all the rest of it." (IP 1, L 176-180).*

As one participant states, it provides a sense of *"comfort" (IP 9, L 633)*, being able to talk to someone.

> *"So, I took some comfort in that, I think, and I felt that I could talk to [Name] and [Name] anytime, because they were great." (IP 9, L 633-635).*

Having someone understand or perhaps going through a similar situation is also shown to be helpful.

> *"I have a friend at the bridge club, who is in the same boat, but his wife reacts in a different way ... he's got a calmer attitude to it, than I have." (IP 5, L 166-168; 177-178).*

Having an outlet, whereby they are able to share concerns appears to indicate a positive mechanism to support coping. Otherwise, it may build up and require a release that is unexpected or unforeseen.

> *"I drove to [Son's], and I don't even know how I got there, I just got out the car, and he was in the drive, clearing his van out. He looked at me, and said, what's up mum, and I just broke my heart, and I hadn't cried for a long, long time, and I think perhaps that did me good, I don't know. But, he has been very, very supportive." (IP 4, L 356-362).*

If family or other support networks, such as friends or work colleagues are unavailable, many of the services provide a support mechanism for caregivers to access. Ideally, this would allow family members to share their concerns with professionals, such as a representative from the Admiral Nurses Service.

> *"Though, saying that, I didn't know what to expect with [Name], the Admiral Nurse, and I suppose, in a way, she's not counselling, but she's listening, and then telling me things. So, you know, in a way, she's advising and ..." (IP 2, L 474-478).*

> *"I mean, I'd be bereft if I lost my carer, she just wraps around you, she's there for you, always optimistic." (IP 5, L 888-889).*

Many expressed feeling guilty about their need to discuss the difficulties that they were having and talking about their CR.

> *"I don't know where I'd be, even just somebody to talk to. When [Admiral Nurse] comes, sometimes I see her away from the house, because I can't talk about [Husband] in front of him ... I don't like him to think I'm talking about him, behind his back, type of thing." (IP 4, L 1068-1071; 1073-1075).*

> *"... because, you can't share everything, particularly when they're your parents, your relatives, how can you. You can't say, hey look, you're a pain in the arse, you can't, that's not on, so what do you say, nothing." (IP 8, L 482-486).*

One participant in particular endorsed the value of speaking to an independent person who was removed from the situation, to provide an unbiased evaluation and opinion of the situation and a separate viewpoint from their own.

> *"Because, I went for this counselling, and I thought, I don't really need it, you know. And, I remember, by the end of the session, being in floods of tears, and really cathartic, you know. I thought, gosh, yes ... I think it would be good to talk to somebody independently" (IP 9, L 961-964; 1391).*

They emphasised a need for being recognised, that they were *"doing a good job, pat yourself on the back, it's hard what you're doing" (IP 9. L 1396-1397).* This indicates that, not having an outlet does not just equate to having *"a valve that you can actually release to someone" (IP 8, L 487-488) "who is good at listening" (IP 9, L 1412)*, that something else is also required. It may be that that they need *"someone telling you that you're dealing with the frustrations well" (IP 9, L 1407-1408).* From this, some participants recommended that a regular outlet is required. This would allow them the chance and opportunity to appraise and reflect on their circumstances and their own abilities to manage the situation.

> *"There needs to be, at least, a weekly, sort of, getting rid of everything in your head, there has to be ... That's what I'm searching for, a weekly release with someone, but not in a formal setting, where you think, oh, it's a bloody counsellor, you know." (IP 8, L 530-532; 536-538).*

> *"But, it would be nice to know you had a counsellor, or something, to just talk through things with on a bit more of a regular basis, have that facility there. Even if it's a phone call." (IP 7, L 492-496).*

Participants found the use of having an outlet supportive in coping with their caring role. Some found great benefit in having an independent listener, separate from the family, which allowed a different perspective and viewpoint to aid in potential problem-solving processes.

4.4.8.3. Organisation and planning

Five participants (45%) have adapted to their role through the use of forward planning, in an attempt to master their environment. This may be indicative of striving to assume some semblance of control, in an otherwise unpredictable situation. Being well organised and using problem-solving techniques, are seen as adaptive coping strategies, that help support the reduction of stress.

> *"So, I don't know whether I've been very lucky, I don't know, or whether it's the way I've took things on board and done the things. I think it's easier to stick your head in the sand, and just deal with the immediacy, but I've done as much forward planning, and taking into account." (IP 4, L 886-892).*

The phrase 'head in the sand' is used, suggesting that it would be easier to dismiss many of the more unpleasant factors that could be involved in providing care. This, again emphasises, that some form of organisational planning and forward thinking is a strength to support the coping process. From the interview data, it is also more likely that the individuals who use this form of coping were co-ordinated and organised individuals prior to taking on their caregiving role.

> *"So, I've just taken all that on board, that's fine, I'm quite happy with that, because I've always been the organiser person in the house, anyway." (IP 9, L 335-338).*

> *"I mean, I suppose, I'm a bit organised, probably over organised in some respects ... I'm probably an organised person, that's who I am." (IP 6, L 151-152; 173).*

The participants who tended to favour organisation and planning, found it useful in order to support them to cope with caring for their loved one with dementia.

4.4.8.4. Plodding on

In contrast to being organised and having set plans in place, seven participants (64%) *"just, sort of, went with it" (IP 7, L 98)*. They attempted to maintain a purpose, in spite of the difficulties they encountered as caregivers. Many used the phrase 'plodding on' to express this outlook.

> *"We're plodding on, that's all I can say, we're plodding on." (IP 10, L 352-353).*

> *"... basically, we're just plodding on together." (IP 4, L 252-253).*

> *"I'm aware of that, but as long as I can I'll keep plodding on, and that's the way I feel about it" (IP 3, L 166-167; 688-689).*

This conveys a sense that, at time, it is better to *"just go with it" (IP 9, L 537)* as plans may make it more difficult, when a flexible and adaptable process may be more suitable, dependent on the circumstances.

> *"... because it's been gradual, you're more able to cope ... because it's been a gradual process, I knew as much as I needed to know initially, and then, as I say, everything has just ... because everybody is different, as I say, they call it a journey, every person's journey is different, so just go day to day" (IP 4, L 1116-1117; 1119-1121; 1123-1125).*

To emphasise the individualistic nature of caring for someone with dementia, this participant uses the phrase *"every person's journey is different" (IP 4, L 1125-1125).* This suggests that for some, problems or difficulties that arise will be dealt with and require some flexibility, *"as and when they crop up, they're being addressed" (IP 4, L 1083-1084).*

For some participants, persevering amidst difficult circumstances has allowed them to cope as things have become more and more difficult, by allowing things to evolve naturally and adapting to the situation as it arises.

4.4.8.5. Using support available

Most caregivers have used external resources to facilitate coping. Nine (82%) made use of primary support services, such as, their partners or spouses, and any grown-up children.

> *"I mean, as I say, one of the objects of coming here, was that my daughter could give me a hand, which she does." (IP 6, L 160-162).*

> *"I'm lucky I've got such a supportive husband, because I don't think I'd have managed it, if he was anything less." (IP 9, L 966-968).*

> *"I couldn't do it on my own, fortunately, my son has been here on most occasions." (IP 6, L 447-448).*

Some participants have relied on their support networks of friends and work colleagues, as another method to manage their caring role, either as a source of brief respite or as a support mechanism for the CR themselves. This appears to be accessed secondary to the immediate family network.

> *"I've got a few friends, and I try to go back on a Saturday night, for an hour, to meet a couple of them in [Town]." (IP 6, L 644-646).*
>
> *"I enjoy meeting my friends once in a while." (IP 10, L 68).*
>
> *"Luckily, I've got some great colleagues at work, and quite often I'd have a bit of a mini breakdown at work and start bawling." (IP 9, L 623-625).*
>
> *"He's got one work mate, who comes, on a regular basis, once, perhaps twice a week ... he'll do anything he can to help [Husband]". (IP 4, L 696-698; 703-704).*

One participant emphasised that *"you have to find what works for you, what's best for you" (IP 1, L 775-776)*, as the best way of utilising existing support mechanisms. A third resource that is mentioned, appears to be a wider communal source for support that some participants have found invaluable.

> *"Several people have asked me, have said to me, if you need any help just give us a call, so I know there's people around. My neighbour at the back, she's so good, she's very good." (IP 10, L 285-288).*
>
> *"If there was a problem here ... perhaps the neighbour came past and noticed something ... If there was a problem, or something going on, I feel quite sure that they could get in touch with me." (IP 3, L 124-126; 128-130).*

> *"And then, we've got one or two other close friends who come, a neighbour across the road, well, we're friends now, we've been here 20 odd years, she comes once/twice a week, just to see how he is, and have a natter. So, round here, everybody knows, and they are very supportive." (IP 4, L 704-709).*

This participant emphasised that *"everybody knows" (IP 4, L 708-709)*, which suggests that this relieves some of the burden, as *"they are very supportive" (IP 4, L 709)*. Perhaps this is indicative of having a safe circle around those concerned, to help relieve the sense of burden.

The participants have shown that the use of internal and external social resources are able to assist in their ability to adapt to their circumstances. The wider the social network, the more likely the safety of the CR can be entrusted, especially as the caregiver is unable to be present at all times.

4.4.8.6. Other coping strategies

This code reflects the use of other adaptive and maladaptive coping mechanisms that participants have found useful. Ten caregivers (91%) have used alternative strategies to cope better. One participant emphasises his need to keep busy,

> *"I just keep busy round the house, basically. I mean, I've always been ... I might be tired, and all the rest of it, but I hate sitting down, you know what I mean, I'm always on the go." (IP 1, L 192-195).*

This may be suggestive of needing to keep physically active in order to keep their mind occupied. This may be seen as defensive, so as not to think too deeply or become too emotive when thinking about their situation. This could also be viewed as maladaptive, as they state,

> *"Consequently, I do overdo it, and I'm work out, but I'm always on the go." (IP 1, L 195-196).*

Humour seems to be strongly emphasised by many of the interviewee's as a positive resource.

> *"Yes, you had to try and laugh a lot, really, and laugh with her, and stuff" (IP 7, L 392-393).*

> *"Yes, we had a laugh, on a number of occasions." (IP 9, L 451).*

Some, although, making light of the situation, felt it is important to be realistic, to support the process; as this participant expresses,

> *"Although, every time we meet he says, have you killed her yet. But, I know it's black humour, but it's the only thing that breaks the monotony, and makes you feel as though you've got some sort of life." (IP 5, L 178- 182).*

One participant emphasised their use of meditation exercises and practice as a means to cope.

> *"The meditation really is about ignoring the small self and bringing the higher self to the fore anyway ... for me it's a godsend." (IP 8, L 106-108; 136).*

Another participant mentioned the use of reminiscence to think about the past in a positive light.

> *"I have a tendency to remember good times ... It's rather than having negative thoughts, and how bad things are, and all that, have a good thought. Instead of feeling bad about yourself, that you can't do this, or you can't do that, or, you can't help anymore, or whatever, try and have a tendency to remember something good, or focus on something that was nice ... I mean, I know she is my mum, when I see her, but I*

> *don't look at her as she is now, I look at her ... when I see her now, I see her as she was, which helps." (IP 1, L 691-692; 701-707; 721-724).*

This participant relates his memories from the past, to help him cope in the here-and-now. This suggests that some form of the CR is maintained in the eyes of the caregiver, without them being completely lost to the disease.

In terms of maladaptive coping strategies, only one participant mentions their use of alcohol, with the realisation that they were struggling to adjust to the situation.

> *"Well, I think I drank a lot more alcohol, to be honest ... But, yes, I felt ... So, the first thing, [Husband] would say, would you like a cup of tea? I would say, no, I do not want a cup of tea, I'll have a glass of wine, thank you very much. And then, you have one, and then that leads to the next, and there were times I know I was drinking too much. But, it was just all the pressure, and I didn't really know how to ... I couldn't escape from it, you know, apart from going out. I do feel a lot more now." (IP 9, L 694; 721-729).*

Some participants made use of other adaptive resources to facilitate their coping abilities. These may have stemmed from personal characteristics and learnt behaviours that have worked in the past. It is interesting to note, that only one participant shared a maladaptive coping strategy.

Overall, participants interviewed in this study have shown varying methods in adapting to their individual situations. It appeared that positive adaptation to adverse circumstances allowed individuals to continue with their role, as caregiver, and cope with increasing demands with diminishing resources. The two main methods from this theme were, firstly, being able to talk to someone and, secondly, removing themselves from the situation.

4.4.9. Evaluation of support services

This theme reflects the interviewee's evaluation and utilisation of available support services. Three codes, interpreted from the data, contributed to this theme. Firstly, participants provided a variable assessment of their involvement in accessing and using formal services. Secondly, based on their experiences, they have provided their preferences of support that they would access, and finally, some of the barriers that they have encountered through their experiences.

4.4.9.1. Support experiences

All participants (100%) provided evidence in relation to this theme. The majority related positive experiences of support that they had received from services, such as the Admiral Nurses Service and Alzheimer's UK. Most were grateful for the support that was provided to them and expressed their satisfaction with the help that was provided in looking after their CR.

> *"I have to say, at this stage, the help, advice, recommendations, from Telford and Wrekin, have been absolutely ... and the GP, which is where it all started, I cannot fault them." (IP 4, L 201- 204).*

> *"I don't honestly think they could have done a lot more. I mean, we had everything in place, everything we were offered in place, regards caring, and everything." (IP 1, L 669-673).*

> *"We've had really good support from all the agencies around, and I've known who to ring." (IP 9, L 1180-1182).*

> *"Well, I've been given very, very good support. I've got no complaints in that direction, and they are always trying to improve things, to find things for us to do ...*

> *But, I am surprised that there is so much support available, and they are such lovely, lovely people." (IP 5, L 873-876; 882-884).*

This participant expressed their 'surprise' at the amount of support that is available, and their gratitude that the area *"does seem so well developed in this type of illness" (IP 5, L 993-994).* It is worth noting that, one participant's experience of different counties emphasised the difference in service provision between localities.

> *"I mean, the services here, compared with [County] are a lot better, much better. There seems to be more awareness of the problem." (IP 6, L 637-639).*

> *"I've also used the Age UK, because when we were in [Town], [Wife] used to go to a day care centre, that was organised by Age UK. I thought they'd got the same situation here, but they haven't, because Age UK have got one or two-day care centres, but it's not the same as it was in [Town], which is where it was, when we were at [Town]. Here, it was run by volunteers, whereas at [Town] it was run by professionals, you know." (IP 6, L 578-586).*

Another participant emphasises their 'luck' that they had received a good service.

> *"I think we must be very, very lucky, I don't know whether it's a postcode lottery, or what, I don't know, but I will not have anybody criticise, or whatever, the help, advice, support." (IP 4, L 950-953).*

This suggests that the expectation of caregivers for formal dementia support services are low, as the following participant relates,

> *"But, I am grateful, because the support we had was very good. My opinion of social services before that hadn't been brilliant, because my sister's partner had, what I think probably now was some type of dementia, a few years ago, and she got*

> *absolutely no help at all. They were terrible, so I wasn't expecting much, but they were brilliant, pretty much on the ball right from day one, from once mum was diagnosed, and everything, so it was really good." (IP 7, L 27-35).*

For those who have received support from services, most felt that it was provided at the right time and if anything was required, support was accessible.

> *"But, as anything has cropped up, help has been offered ... And, those are all free of charge, so it is excellent, the help and advice, and physical support, in as much as whatever they can give us to help." (IP 4, L 1099-1100; 1106-1108).*

> *"As I say, I've got a terrific Admiral Nurse and, the thing is, if I've got anything that I want to report, or anything to find out, I've only just got to get in touch with them and say, I'd like to know about so and so, or can you tell me about this, can you fix us up with appointments for drop ins, and things like that ... we haven't been left on our own" (IP 5, L 969-975; 980).*

This participant uses the phrase *"we haven't been left on our own" (IP 5, L 980)*, this suggest that there is a potential underlying fear that they would be left to manage things by themselves and become isolated. Being able to access support, if and when needed, seemed to suit the majority of interviewees. This seemed to allow a more flexible and individualised approach, that would potentially avoid caregivers becoming overwhelmed with information. As one participant relates, *"things were, you know, bombarding you" (IP 2, L 571-572),* to emphasise their experience of being overwhelmed with information.

> *"I don't know, in those first few weeks, how much I learnt, because we had very intensive courses, that the Young Dementia Group set up. And so, things were, you know, bombarding you, and I can't even say that, oh, that was helpful, or, I learnt that, because there wasn't anything that I learnt." (IP 2, L 568-574).*

> *"I think it would have been overwhelming, in the beginning, if I'd have been told everything that I needed to know. Plus, the fact it would have been too much, and I'd probably have forgotten some of it. But, for me, it's been at the right stage, when I've needed to know something I've been told. As I say, I've got no other experience of Alzheimer's, so I can only, sort of, obviously, speak for myself. But, if I've needed anything, or anybody, then there's been people there that would help me." (IP 4, L 1137-1146).*

One participant, however, felt that accessing services on a perceived 'self-service' basis was not helpful from their perspective.

> *"After that, I didn't have any contact with the Alzheimer's Society, they didn't keep in contact. I think it was more, well, we're here if you need us, we've got the drop-in centres, and that was it really ... I didn't find that particularly useful". (IP 7, L 178-181; 185).*

This suggests that participants may find having services approach them, for periodic checks, once they are involved, more helpful. The majority of participants felt that there was *"quite a bit in Telford and Wrekin available" (IP 9, L 1344-1345)*, some mentioning that they were *"quite impressed" (IP 7, L 124)* and had *"no complaints" (IP 3, L 789)*. The Admiral Nurses Service was particularly praised by caregivers.

> *"I have an Admiral Nurse, who comes out to me about once every six to eight weeks. She is superb, I can't rate her highly enough, she has told me things that I didn't know, she has made me understand why [Husband] does some of the things that he does ... That has been wonderful, I can't rate it highly enough." (IP 2, L 247-252; 295-296).*

> *"They are exceptionally good, they've been very good to me. The Admiral Nurses, they couldn't be more supportive." (IP 5, L 807-809).*

> *"I did find the Admiral Service absolutely brilliant. It took me a little while before I could get someone, because there's only a few of them, and we're lucky we've got it in Shropshire, and they need more of them, is all I can say, definitely more Admiral Nurses." (IP 7, L 185-190).*

It appears that a lack of availability of Admiral Nurses may affect the benefit to caregivers, especially as it was deemed as a highly valuable resource. Another source that was deemed a highly supportive resource were Social Workers. For some participants, their Social Worker was a huge support in accessing needed support and equipment.

> *"The Social Worker has been absolutely incredible, her name is [Name]. I don't think we would be in the position we are in today, without her ... The care and support that [Social Worker] gave us, and is still giving us, was above and beyond." (IP 11, L 331-333; 336-337).*

> *"And, I didn't even realise I could have it, until I met a really good Social Worker, who was fantastic, and set it all up for us. I had a lot of help from Telford and Wrekin, I've got nothing but praise for them, to be honest. We've had a couple of little blips along the way but, on the whole, it's been fantastic." (IP 9, L 665-670).*

As this participant relates, the support services are not perfect and are limited in their resources and what they are able to offer.

> *"Then, we had one Social Worker who, kind of, fell off the radar a bit, but I think she was under a huge amount of pressure, because there were a lot of changes. They had restructured, and reorganised, and I think less people doing more for the job, you know, a bit like everything now." (IP 9, L 1085-1090).*

Another participant felt that, even though Social Services were triggered, they doubted whether they would have had the same level of support under different circumstances.

> *"Yes, I think so, because I think, from the beginning, a lot of people don't realise they can actually get help. We didn't, Social Services, it just happened Social Services got involved after the diagnosis, really, and with [Sister] being poorly. I don't know if my sister hadn't been poorly, how quick of the mark they would have been, to be honest, I don't know, because my experience was good that way." (IP 7, L 500-507).*

This suggests that caregivers tend to be cautious, possibly as a protective factor, so that any raised hopes and expectations cannot be diminished. Otherwise, this may lead to a build-up of frustration and disappointment, especially when there is limited support available. One participant relates his experience of accessing a respite service. They found it had little benefit, as it required them to give a period of notice, and therefore, they could not do anything spontaneously or at short-notice.

> *"But, even that's difficult to arrange, because the company that provide the care, for a start off they need two weeks' notice that you want to use them for an hour. It's not much of an advantage really, you know, that was provided, I think they give you 25 hours, but you've got to give them, I think it's a week's notice, or a fortnight's notice before you can use them, which means, if something happens and you want to go somewhere a bit quick, they can't do it." (IP 6, L 649-658).*

Participants who used paid care providers found the quality of service changeable and inconsistent. Often requiring continuous supervision, reducing the benefit of delegating some care duties to a third party. Many expressed difficulties with *"continuity"*, as they had *"issues with staffing" (IP 9, L 1325; 1327-1328).*

A few participants also found it difficult that services did not take into account their viewpoint as a caregiver, most services focussing on the PwD.

> *"... because everyone that comes, it's about the cared for. There's nothing for the carer." (IP 8, 542-544).*

> *"... they are here to support the carer, not the person with dementia. That is a great help, because she sees it from my point of view, whereas the other carers are here to support my mother, and they aren't able to see it from my point of view. So, it's amazing the different takes on dementia." (IP 11, L 299-305).*

> *"Yes, well, that's right, so they're sorted. It's me that's not sorted, because there's no one there. Because, I can see, stand back, and think, they need this, that, and the other, but there's no one there, sort of, saying ..." (IP 8, L 514-518).*

Some participants shared their experiences of feeling patronised and taken for granted by services. One participant argued that if assessed and appraised as needing certain aid, this should potentially come with some level of trust. Rather than adding to the burden of providing care.

> *"Being accountable, it's bad enough that you're arranging care, and trying to make the best of everything, but then it's as if you're being accused of being fraudulent ... And, I find that very, very ... it's patronising, and it's very upsetting. As a carer, I don't think there is sufficient support, because the support is a help group, okay, that might work for some people." (IP 11, L 351-354; 365-368).*

> *"I believe that the council are actually taking the micky out of unpaid carers, you know, it's family that does it, in the main. But, we don't get any respite care" (IP 8, L 331-334).*

Further to this, one participant shared their experience of not feeling listened to by services. Especially as they felt that they were struggling with certain behaviours and their concerns were essentially dismissed.

> *"I felt that he dismissed me then ... is not actually listening to what I'm telling him ... I felt really like I'd been told to be quiet." (IP 9, L 814-815; 816-817; 820-821).*

They use the phrase *"I was pretty honest with him" (IP 9, L 823)*, which suggests that they felt that services thought they were lying or falsifying the behaviours of their loved one.

Some participants felt that continuity of service and face to face contact was vital, in order for services to be able to recognise changes and take more effective action; providing caregivers with a 'peace of mind'.

> *"If things went wrong, and I was struggling, they'd come in and they'd see something isn't quite right and maybe, we could do this for you, maybe the time has come. That's why I want a lot of them involved, and I like them to come to the house. A bit like the memory service, although, where we used to go up to [Village], then the lady used to come to the house every couple or three months, the last couple of times it's just been done over the phone, which I've found is a little bit disappointing." (IP 3, L 348-358).*

A lack of consistency within service provision and lack of communication was also expanded on by caregivers.

> *"I was quite shocked to find out, a lot of the people there hadn't had the same support I had. And, I was thinking, oh, did you not have, did social services not tell you this, they'd go, oh no, no, nobody has been involved, and I've had to find this out myself." (IP 7, L 148-153).*

> *"I've found it's very frustrating, in fact, it's a bloody nightmare ... that the services aren't liaising with one another ...there's no cross over with information, which is more than annoying." (IP 8, L 277-278; 279-280; 292-293).*

Furthermore, another participant who had experience of their CR in hospital, felt that there was a lack of knowledge and understanding by the hospital staff. They felt disappointed as they expected their loved one to be well looked after in a hospital setting, with the false assumption that they would have an awareness of dementia care.

> *"Our experience at the hospital wasn't great either, but I don't think they knew enough, nearly enough, about how to look after somebody with dementia." (IP 7, L 557-559).*

One participant also mentioned the lack of media awareness on dementia.

> *"And, I mean, there's been programmes on the tele about people with dementia, and all the rest of it, and I don't think that nowhere near focuses on what it actually is like for real ... It's so common, but it's not out there, if you know what I mean, in mainstream media and all the rest of it. I know, occasionally, they have these ad campaigns about it, and all the rest of it, but I don't think there's enough done to the awareness of it." (IP 1, L 549-552; 557-559).*

Participant's experiences of support were varied, with some experiencing positive elements, compared to some who felt that they struggled to gain access to and maintain a sufficient level of support. Most caregivers widely acknowledged the support of the Admiral Nurses Service and some tertiary agencies. The inconsistent provision of support and varied experiences reported within the same area is worth noting.

4.4.9.2. Support preferences

All interviewees (100%) provided a wide-ranging view of the type of support that they would prefer. Consistency and continuity from professionals were strongly advocated by participants. It was perceived that this would allow change to be noted more quickly, which would enable professionals to act and provide support in a timely manner. Familiarity with specific professionals would also provide caregivers and their CR with a greater level of comfort.

> *"Yes, but it would useful, maybe, for somebody outside to come in and go, okay, there has been a change." (IP 8, L 731-733).*

> *"Well, it's probably in the sense that, if something is drastically going wrong, the doctor can see a slight change, rather than if it was a new person, they wouldn't notice the subtle changes." (IP 2, L 627-630).*

> *"That person might recognise, it's not quite right, they weren't like that the last time, and maybe make a few more enquiries. But, if it's different people coming in, unless there's a glaringly obvious thing wrong, it could be missed. As I said, that's my thoughts on the matter, I haven't got any …" (IP 3, L 862-867).*

> *"I think, if my experiences are true from what these other people were saying when I went to the meeting, social services need to, sort of, be more consistent, really. It sounds like some people got some help, some had little bits, others had none at all, I think that needs to be a bit more consistent." (IP 7, L 434-439).*

Further to this, one participant valued having face to face contact with professionals, not only to ensure that any changes within the care environment could be noted, also as a means to combat isolation.

> *"I know, I know, is the face to face contact, and people coming to meet people, rather than trying to do things over the phone, is most important, to me personally, that's an opinion ... I think that that's quite important, doing things over the phone is, to my mind, a little bit impersonal, and even if it's only once every three months, instead of coming for an hour, just come for half an hour, but the actual physical, another human being, is quite important. I mean, I wouldn't say we're isolated, or I feel isolated, but we don't get too many people come through that door, in my own house." (IP 3, L 793-797; 801-808).*

The majority of participants also preferred one to one support, rather than accessing a group, as they generally found that they learnt more in an individual context.

> *"Well, because I don't think it would be good going, like, to an AA meeting type thing, scenario, you know, you've got ten people in a room all discussing it. Because, a lot of people can't always, through one thing and another, speak for themselves in a group. I think sometimes, with a one to one, you can get down to the bare bones, really open up, and tell them everything, basically, rather than being in a group scenario." (IP 1, L 611-619).*

> *"I think people need to know a lot more about what carers need, what they want to do, and not just presume that all carers want to go to a meeting and share with other carers, because some of them don't." (IP 7, L 441-444).*

> *"But, I mean, I've done all these other courses on dementia, and caring, and what you do when they're diagnosed. And, out of all of them, although I learnt a lot in the early days, that I didn't know, obviously, I've learnt more from [Admiral Nurse], she comes for an hour." (IP 2, L 272-277).*

It was also felt that, a one-to-one approach afforded a more holistic approach; where all aspects that relate to the PwD can be taken into account, including the people who look after them.

> *"... we have to see it not as individuals, it's the whole thing, you can't take one from the other. You can't just look at my dad and say, that's his needs, and he's receiving this, and tick that, tick that, it's not like that. Because, one person affects the other, you know, it's a domino effect that goes on, on many layers." (IP 8, L 438-444).*
>
> *"As a carer, I don't think there is sufficient support, because the support is a help group, okay, that might work for some people. But, dementia tends to be specific to the person." (IP 11, L 366-369).*
>
> *"So, we need to have a consistent thing going through, that everybody can get exactly the same help, and they need to find out what their needs are, and go with that, and not just presume." (IP 7, L 458-461).*

Having a holistic approach would also allow caregiver stress to be more easily identified and managed.

> *"You need to have that support there, to tell you, I know you feel guilty but, because you're not going to be able to cope on your own, you need help." (IP 7, L 519-522).*
>
> *"I was aware that stress was building up. I didn't tell my parents. So, yes. But, equally, you know, again, folk should be looking out for it. I say to the Admiral Nurse, look, I'm stressed, be aware of this, you know, I need to manage this, and I need to manage it now." (IP 8, L 401-407).*

The majority of participants stressed the need for more respite to be available in order for them to take a 'break'.

> *"This is me and all of the me timers probably, is respite for them ... every one of us says that it would be nice to have that time, when you're totally on your own." (IP 2, L 389-390; 395-397).*

> *"Respite care for the carer, that their cared for are actually cared for, while they go and take some quality time out." (IP 8, L 329-331).*

A few participants suggested more respite care should be available in their own home, rather than within a care facility.

> *"There needs to be more services, there needs to be more care available in your own home, to allow carers to have free time." (IP 11, L 412-414).*

> *"... the cared for can be in their own home, particularly the dementia folk, because that's what they're used to, they're familiar with it." (IP 8, L 353-355).*

One participant mentions the Admiral Nurses Service, that there was a need for this particular provision to be increased.

> *"I did find the Admiral Service absolutely brilliant. It took me a little while before I could get someone, because there's only a few of them, and we're lucky we've got it in Shropshire, and they need more of them, is all I can say, definitely more Admiral Nurses." (IP 7, L 185-190).*

Several participants stated that, they would have appreciated a breakdown of what to expect from the beginning and more in-depth information about dementia.

> *"If someone had sat down with us, from the word go, and said, right, this is what it all entails, this is what it's going to be, and this is how bad it's going to get ...*

explained what the mechanics of it all were, we'd have had a better understanding and known then exactly what we were dealing with, instead of coasting on by, just picking up bits as we go." (IP 1, L 649-652; 655-659).

"I think I would have liked to have known that there was more funding available earlier. That probably would have helped tremendously ... I think that's, as a carer, it would be beneficial to know immediately what funding is available, what care is available, what quality care is available, and what respite is available for carers." (IP 11, L 433-435; 440-444).

"So, yes, I think, right from the beginning, someone needs to say, right okay, your mums got, or your dad's got Alzheimer's, or whatever it is, and just to explain what a strange journey it might be, right from the beginning a lot more. And, to keep on top of it, really, and to make sure people have the help they need." (IP 7, L 508-515).

One participant mentioned the logistics of travel to make it more convenient to access certain groups or meetings.

"Once a month, on the third Tuesday. I wish it was a meeting held at Meeting Point House, because I could get there very much easier." (IP 10, L 172-174).

The majority of participants preferred one-to-one contact, in which several needs could be met; including information sharing and identifying changes. Some wanted more of an in-depth breakdown of information from the outset; assuming to better prepare them for any forthcoming eventualities and changes.

4.4.9.3. Support barriers

Ten participants (91%) shared their experience of the difficulties that they have found accessing services. The main barrier to support that they found, was a reluctance from their CR to access services, including respite.

> *"He doesn't want any help, he's never wanted ... So, he's very difficult to help, and now, as he's getting worse" (IP 2, L 8; 13-14).*
>
> *"Because, my mum, at first, was totally against having anybody come in, she said, no, no, I'm not having anybody come here ... Obviously, we had to step in and say, look, you can't carry on. And, they put the carer people in, they started off coming once in the morning, to sort them out, then at tea time." (IP 1, L 351-353; 356-359).*
>
> *"Because, [Husband] refuses to go anywhere, to do anything, to be anywhere else, he will go out with our son, so that is a bit unfair, sometimes [Son] tries to take him out, so he does go out with [Son]. But then, I've still got [Daughter] so ..." (Interview participant 2, lines 255-260).*
>
> *"Yes, especially the walking, because I find that, I can't go anywhere, or do anything with him, he refuses to go in a wheelchair. And, he's like this, and I find that very, very stressful, for want of a better word. But, all the way through, [Husband] is a very strong person, shall we say, he will only do what he wants to do ... He won't go anywhere, as regards clubs, or anything like that." (IP 4, L 54-60; 209-210).*

This may be due to some perceived fear by the CR, of being moved into a care facility on a more permanent basis; or a reluctance to see others in a similar or worse condition as themselves.

> *"So, the whole of my life, centres around making sure that my mother is safe. She desperately does not want to go into a home. We've tried her on day care, and she absolutely hated it, and it took days to settle her down again. She was anxious, terrified that she was going to be put in a home, and it was very, very distressing, for both my mum and myself." (IP 11, L 51-57).*

> *"[Husband] refuses to go into respite care, I think he thinks, if he goes in he won't come out." (IP 4, L 830-831).*

One participant expressed their reluctance for respite, fearing that their CR would not remember them when they returned.

> *"I mean, this business that [Name], from the Admiral Nurses, she's trying to get me a couple of weeks respite, what worries me about that is that, if [Wife] is away for a couple of weeks, she may not know us when she comes back." (IP 6, L 554-559).*

One participant felt that some services did not have long term benefits for their CR.

> *"It was great that mum was in the other room, they were doing little things for her, but I don't think it had any long-term benefit for her at all. She didn't know really why she was there, and what she was doing, so I don't know if they carried on with that project." (IP 7, L 173-178).*

The second major barrier that participants encountered was around the logistics of accessing support services. The main difficulty was 'fitting it in' around employed work commitments or appointments.

> *"I think there's lots of support out there, it's about being able to access it, and having the time to get to it. If I wasn't working, it would have been different." (IP 9, L 1307-1309).*

> *"There are other things that I can access with the carers me time, but it's finding the time in between all the appointments, all the slots." (IP 2, L 330-332).*

> *"... on the caregiver's thing, I think it was, because you could have these day out things, to [Museum], and stuff like that, which was really nice to do. I thought that was lovely that you could do that, I didn't get chance to go and use it, but I had intended to, it was just difficult ... It was timing, and when things had come up." (IP 7, L 226-232; 236).*

> *"Yes. And, the services, it's as though I'm being awkward, I can't fit them in. No, I actually can't." (IP 8, L 630-631).*

> *"We do have these pamper sessions, there's only been one in [local Village] though, they're normally at [Village]. And, it's a morning session, it takes too much out of the day, I have to leave [Husband] on his own too much, whereas in [local Village], it wasn't so bad." (IP 4, L 990-995).*

Another issue around logistics that some participants felt, was the need to be available if the CR accessed a day service. Timings could not be guaranteed and, therefore, caregivers were waiting around for their loved one to return. This would in effect cut short any respite.

> *"... it was difficult, with me working, arranging the logistics. I'd have to be here to see my mum off, and it was a bit of a problem, me not being here to receive my mum, when she'd been to the day care, and it didn't really work." (IP 3, L 512-516).*

> *"But, I mean, even then they can't guarantee getting her back at a certain time, because they've, obviously, dropping people off at different places ... I mean, when they bring her back, they can't say, we'll have her back at 4 o'clock, you know, sometimes it's after 5 o'clock, so you're watching out for her from four to half past five." (IP 6, L 246-249; 254-257).*

A few participants stated that, they had not taken advantage of some of the support available as they are unsure how they could benefit from them.

> *"I haven't been in touch with social services, I don't know how they could help me, really." (IP 10, L 192-193).*

> *"That's how I became aware of these sorts of services, but we don't really take advantage of them ... What can they really do?" (IP 3, L 448-449; 453).*

One participant expressed that it would not make a day-to-day difference if services were involved. They expressed that for them, it was more about when things deteriorated and being aware of who to access if the need arose.

> *"It doesn't make a great deal of difference in my life, and my day to day things, whether the Admiral Nurses or the Memory Clinic are particularly involved or not. Do you understand what I'm saying? My day to day, they have no effect on it. To me, I'm involved with them, or I have any sort or relationship with them, it's in case things go wrong, if I find I can't cope. If I was thinking things were going wrong, and I was unable to cope, I'd have somebody at the end of the phone I could ring and, I hope, would be able to respond and say, you probably need to do this, or you probably need to do that. It's a phrase I use is, I've got them in my back pocket, yes." (IP 3, L 464-477).*

A few participants valued their independence and were disinclined to ask for support when they felt they were able to manage.

> *"I don't ask for help, I just like to be independent ... Until I can't do it myself." (IP 10, L 292; 296).*

"They do seem to have it all tied up, there's help there in all directions, if you want it. But, I'm an independent person, and I like to keep going." (IP 5, L 995-997).

"But, I didn't want anyone to come in, it was another commitment I didn't want to have to have someone in here at a certain time in the day" (IP 6, L 48-50).

The main barrier that participants expressed were CR's reluctance to access or attend services. Furthermore, caregivers pointed out the logistic difficulties they faced when attempting to fit their care duties around other commitments.

Overall, the majority of participants provided a positive evaluation of services received. Their preferred support service was based on their ongoing experiences of the benefit they perceived. The most preferred support was one-to-one contact with known and familiar professionals. It was pointed out that some of the barriers encountered related directly to their CR, rather than the caregiver themselves. This information could prove useful in providing recommendations to support services.

4.4.10. Framework analysis

A framework approach was used following the completion of the TA methodology, allowing for the comparison of the different groups (identified in Phase I) in a qualitative paradigm (Ritchie & Spencer, 1994). Table 15 provides a summary that sets out the different groups that participants were allocated to, depending upon their scores from the PRM and SF-36v2 measures.

The seven themes will be discussed separately, below, in relation to the characteristics of each group. A summary framework for each theme is provided in Appendix S.

Table 15

Group summary matrix

	High resilience	Low resilience
High wellbeing	Group 1	Group 2
Low wellbeing	Group 3	Group 4

4.4.10.1. Framework 1: Diagnosis facilitates access to support

Participants in group one noticed a gradual decline in their CR and instigated GP contact and subsequent referral to services. Group two raised concerns with their GP, on their own, and initially, CR diagnosis of depression was raised; which was stated as being the *"best option",* as the *"alternative is a lot worse" (IP 3, L 409; 403).*

Participants in group three had noticed the gradual deterioration of their CR, although one participant seemed to be uncertain, until a specific incident highlighted the potential severity of the situation: *"... we haven't broached the subject, although they've been noticing the deterioration, the same as myself. Then, we just decided that we'd got to talk it out and do something about it ..." (IP 5, L 217-220).* Participants in group four either had to be triggered by a specific event to seek support or were prompted to seek further advice by a friend.

The majority of participants (*n*=10) received a diagnosis and were felt enabled to seek out support from available services. One participant in group three found it difficult to get a diagnosis and, therefore, struggled to gain access to services. It is also worth noting that a participant in group four questioned their CR's diagnosis, *"... I'm not sure if he's got dementia ... it's easy to put a label on folk ... I think it would be useful if dementia patients were reassessed, not just put a label on them" (IP 8, L 5; 88; 718-720).* Although, *"he's been* *labelled that, which is fine, which means he gets extra, sort of, folks, seeing how he is, and so on" (IP 8, L 20-22).*

The above framework suggests that participants in groups 1 and 3, with higher psychological resilience, seemed more likely to initiate the process for obtaining a diagnosis in comparison with the other groups. Overall, groups had similar outcomes of receiving support, once they instigated a diagnostic assessment procedure, primarily through their GP.

4.4.10.2. Framework 2: Relentless deterioration

All four groups communicated a sense of helplessness, with the degenerative nature of dementia, expressing little hope of improvement. The experiences of increasing demands on time and increasing tasks were also similar across groups. Six participants, across all groups, felt that the escalation of their caregiving role was a gradual process, taking place over a long period of time, *"one day you totally do whatever you want whenever you want, to having the responsibility of being a carer, it doesn't happen in 24 hours" (IP 3, L 64-67).*

The majority of participants (*n*=10), across all four groups expressed that a greater dependency from their CR had developed in line with the progression of their condition, *"I now do everything" (IP 2, L 105).* This increased reliance, upon the caregiver, was associated with the sense of feeling restricted and tied, especially in relation to the caregiver's own pursuits. A lack of spontaneity and *"not being able to do what you want to do" (IP 2, L 139-140)* was expressed as the most difficult aspect.

There were some subtle differences between participants, on the extent of how constrained they felt, which varied with the dependency of their respective CR. Group 2 stated how they were beginning to experience difficulties leaving their CR for long periods of time, with the increasing impact on their leisure, social and employed work commitments. Whereas, the other groups appeared further down the path, expressing they already felt *"totally committed" (IP 6, P 94)* and prioritised the needs of the CR above their own.

Of note, spousal caregivers related more of a sense of being *"stuck 24 hours a day, seven days a week" (IP 5, L 72)* with *"no escape route" (IP 4, L 940)*, as compared to ACCs.

Overall, the groups voiced subtly differing views of their experiences of dementia in their CR, and the resulting impact on their lives; the issue appeared less in relation to levels of psychological resilience and more in relation to the familial relationship with the CR.

4.4.10.3. Framework 3: Caught in the middle

This theme captured the difficulty of balancing their current lives with their existing commitments and any new developments. Participants in groups 3 and 4 showed greater difficulties coping with their own physical ill-health, compared to the other groups (who had higher wellbeing scores). Thus, their ability to provide care and carry out tasks may well be impacted over time.

Furthermore, participants, who were full-time caregivers, were more likely to express the loss of a planned future. This tended to be stated using emotional-laden words, such as, "*cheated"* and *"angry, upset" (IP 4, L 279)*. Spousal carers highlighted particular losses; for example, the loss of a confidant, *"you've got nobody to talk anything through with" (IP 2, L 663)*, and the loss of the marital relationship, *"I've removed myself from being his wife" (IP 4, L 290-291)*.

Overall, the main differences were related to that of being a spouse. There was a small difference also noted between the high and low wellbeing groups.

4.4.10.4. Framework 4: Unsustainability

Participants in the higher psychological resilience groups (Group 1 & 3) recognised a limit in what they were able to offer, in terms of providing care to their CR, *"you can only do what you can do" (IP 1, L 478-479).* Whereas, participants in the lower psychological resilience groups (Group 2 & 4), foresaw a time when there would be a 'breaking point' resulting in the relinquishing of their role: *"how much time she's got before it becomes impossible for me to look after her" (IP 6, L 690-692).*

There was a further difference, between the groups, regarding their abilities to maintain their primary caregiver role. This depended, once again, on their CR's capabilities. Some retained a level of independence and could, therefore, be left for a set amount of time, whereas others *"realised somebody needed to be in the house all the time" (IP 7, L 274-275).*

All groups stated a desire for domestic support, and those with higher psychological resilience, Groups 1 and 3, were more likely to seek assistance, than those with lower psychological resilience (Groups 2 and 4). In the case of caregivers wanting respite, those with lower wellbeing scores were more likely to voice the need for respite (Groups 3 and 4).

Overall, participants in all groups recognised that providing care with an increasing dependency is unsustainable in the long term. Their evaluation as to the level, to which this could be continued, however, differed.

4.4.10.5. Framework 5: Adaptation, adjustment and effects on care

Participants in all four groups could relate specific examples and events associated with the 'metamorphosis' of their CR. As the transformation proceeded, the majority of participants developed techniques to assist in care tasks, mainly through a method of 'trial-and-error'. Those in the higher psychological groups (Groups 1 and 3) were more likely to compromise or find something similar to do, *"or we'll have a takeaway, that's the easiest, because we don't* *have to take him anywhere then" (IP 4, L 776-778).* Most found strategies as a *"way to get round" (IP 9, L 107-108)* difficult behaviours or were continually trying to find solutions as problems manifested, *"it's constant adapting" (IP 7, L 408).*

Most participants expressed a sense of responsibility to look after their loved as best as they can. ACCs were more likely to express a feeling of 'returning the favour' of being looked after when they were growing up and wanting to provide the best care that they possible can. Maintaining the CR's independence as long as possible was also an important factor that was taken into consideration, *"I didn't want to ... deskill her in everything" (IP 9, L 124-126).*

All groups portrayed a sense of self-doubt in whether they were making the right decisions in terms of providing care to their CR, *"you think you're doing the right thing at the time" (IP 9, L 1484-1485)*; most appraised their decisions as being in their CR best interest.

Overall, participants in all groups have made some adaptations to their abilities when providing care to a PwD and adjusted to their situation over a prolonged period of time. There were minimal differences between higher and lower psychological resilience groups.

4.4.10.6. Framework 6: Coping strategies

Participants utilised varying methods to help them manage their role as caregiver to a PwD. Those in the higher psychological resilience group were more likely to have a variety of coping strategies and were more protective of their respite, *"nothing gets in the way of that" (IP 2, L 50-51).*

All four groups provided evidence in relation to using support networks, this varied between family and friends, neighbours, work colleagues and paid carers as the type of assistance they relied on. One participant in Group 4 mentioned using their Church as a form of spiritual and social support, *"there's things going on there ... I've got a bit of a social life there" (IP 10, L 81; 86-87).*

The sources that participants sought for relieving their distress were varied, ranging from personal to professional assistance. Those in the higher psychological resilience groups, however, appeared to have more than one outlet, with a greater focus on enjoyment, compared to the lower psychological resilience groups.

Overall, participants across groups adopted similar coping strategies to varying degrees. Participants that scored high on the psychological resilience measure, were more likely to have a wider range of coping mechanisms and use them with positive affect, compared to those with low psychological resilience scores.

4.4.10.7. Framework 7: Evaluation of support services

Participants in Group 1 had experience of arranging placements through Social Services that required 'forceful' action. Whereas, participants in Group 3 and 4 expressed their difficulty in arranging support, *"even if you scream and yell ... you still don't get anything" (IP 8, L 545-547)*, *"I'm a particularly strong person, and the fact that I couldn't get it done" (IP 11, L 457-458).*

The majority across groups expressed their concern with regards to the lack of consistency and continuity amongst service providers. Most felt similar in their opinion on having services provide regular and consistent one to one contact, preferably with the same person, *"it's probably in the sense that, if something is drastically going wrong, the doctor can see a slight change, rather than if it was a new person, they wouldn't notice the subtle changes" (IP 2, L 627-630).* This sentiment was shared by several participants, *"that person might recognise, it's not quite right, they weren't like that the last time, and maybe make a few more enquiries. But if its different people coming in, unless there's a glaringly obvious thing wrong, it could be missed" (IP 3, L 862-866)*; *"it would be useful, maybe, for somebody outside to come in and go, okay, there has been a change" (IP 8, L 731-733).*

Participants in the lower wellbeing group appeared to have had more support in physical aids and equipment from support services. They were also more likely to struggle to ‘fit in’ services provided for caregivers, due to their own health difficulties, *“I was going through treatment as well, and I couldn’t make all of them” (IP 7, L 145-146)*; or those of their CR *“there’s other medical stuff going on at the same time” (IP 8, L 35-36).*

Overall, groups evaluated support services similarly across different areas, although some experiences were markedly different.

4.5. Discussion

The qualitative phase of this study set out to further illuminate the experiences of dementia caregivers. The use of a semi-structured interview approach allowed a more in-depth assessment of the factors that influence individuals to undertake a caregiving role, their adaptability and use of coping mechanisms to maintain their role, and how this may affect their ability to seek and access support.

4.5.1. Findings

TA of the data identified seven themes, with several codes for each (see Table 12). The themes are not, of course, mutually exclusive of each other. Below, each of the research questions will be discussed in relation to the individual theme analysis, followed by the findings from the group framework.

4.5.1.1. RQ1: What factors influence individuals to modify their caregiving role over time?

The experiences and circumstances of the participants varied, however, most acknowledged that their responsibility increased, as the reliance on them by their CR became more pronounced as the condition progressed. The majority of participants seemed to agree that their role did change gradually over time.

Most expressed a sense of obligation or responsibility of having to look after their loved one. Interestingly, this perspective was most often expressed by ACC. This supports previous research findings where, despite high incidences of negative outcomes reported, caregivers wanted to provide care for their CR (Stockwell-Smith, Kellett & Moyle, 2010); many seeing it as an opportunity to repay past kindnesses or fulfil obligations (Zapart, Kenny, Hall, Servis & Wiley, 2007).

From the interviews, there were two common threads which could be identified. The first, was the observation of their loved one showing signs of change and deterioration. This was not just a change with age or physical illness, rather they were observing significant cognitive and emotional changes, such that, the person was becoming unfamiliar to them. The theme 'adaptation, adjustment and effects of care' reflects the changes and learning required, when faced with a brain disease that can radically alter the presentation over time, on multiple occasions, and no longer represent the person the caregiver once knew. In this context, the caregivers were honest about their own insecurities and the compensatory mechanisms, such as, knowingly seeking unattainable levels of care.

The second thread reflects how the changes in the CR brought new challenges to adapt and role reversal, especially in the case of ACC. The theme 'unsustainability' reflects caregiver's acknowledgements that their roles will need to adapt and change as the condition progresses and deteriorates. This included relating practical and other supports that have been adopted in order to continue their caregiving role, such as domestic help and assistive technology.

The theme 'caught in the middle', captured obligations felt over desired choices, where upon the caregiver's sense of duty pushed aside their own self-fulfilments and wellbeing. On one hand, this was seen as a physical struggle, in terms of their commitments to work, other family and other dependents, and, on the other hand, the high levels of distress felt with the increasing strain on their capacities to cope.

Overall, a reflected view from caregivers was of a spiralling commitment to care which had the consequences of feeling almost imprisoned, in their concern to dutifully look after their CR. They sublimated their own needs on an ever-increasing scale, slowly losing a sense of freedom and self-determination.

4.5.1.2. RQ2: To what extent do resiliency and wellbeing (physical and mental health) factors impact on caregiver's perceptions of providing care?

Several themes and codes were identified that brings together aspects of a caregiver's perception of the declining process within their own internal characteristics and their use of coping strategies.

Firstly, coping strategies were discussed by the participants, who identified a range of mechanisms that they used, in order to manage their psychological wellbeing and, thus, their ability to 'bounce back' in the face of adversity.

The theme of 'coping strategies' reflected the common and diverse methods used by caregivers to combat the stressors and personal challenges faced in their role. How they managed their way through adverse circumstances, when confronted with an insidiously changing landscape that presented an emotional carousel.

Secondly, participants raised the anxiety of the 'losing battle', the inevitable decline with no hope and the impact on both the perception of their role and on their psychological wellbeing. They also recognised the ever-increasing demands upon them, as the condition progresses, with the consequential restrictions this has brought to their time and quality of life. These perceived 'perpetual commitments', alongside a fear of inadequacy and self-limitations as a care provider, relate to the resiliency of the caregiver and will impact on their meta-analysis of their own wellbeing.

The self-judgement and the perceived view of their declining CR, as set out in the above paragraph, highlights the importance of coping mechanisms required to achieve some balance in the caring role. Thus, positive adaptation to adversity, alongside an individual's ability to use internal and external resources, are defining attributes of psychological resilience. A study by O'Dwyer, Moyle and van Wyk (2013) on psychological resilience in family carers of people with dementia, found that psychological resilience was nurtured through social support, faith, positive coping strategies and personal characteristics. More psychologically resilient caregivers may, therefore, be able to recover better from the pressures of providing care and sustain their role for longer (Zautra, 2009).

Overall, caregivers were aware that the caring role was not sustainable without necessary self-protective processes in place. The course of the dementia was seen as all-consuming in the face of finite resources and capacity from themselves.

4.5.1.3. RQ3: What factors facilitate or hinder caregiver's engagement with support services?

Participants shared a variety of experiences in seeking and accessing support from services. Firstly, the theme, 'diagnosis facilitates access to support', reflected participants overall view that, a dementia diagnosis enabled them to access services and organisations, which would not have been possible otherwise. This included the initial set of circumstances that prompted caregivers to seek a diagnosis. Often, PwD and their families may delay seeking medical professional input until more definitive issues occur (Leung, et al., 2011), or a crisis, that may trigger the pursuit of a diagnosis (Howcroft, 2004).

The majority first sought advice and support from their GP, which in turn led to an assessment process and eventual diagnosis. It was noted that the initial prompt in contacting services would initiate tertiary services and relevant agencies to become involved. This suggests that many caregivers may be unaware of existing services and support available to them, as any access is triggered through professional referrals. This may be important to acknowledge as a factor to be considered when evaluating support services, rather than largely focussing on type of services, their availability or cost-effectiveness (Brodaty, Thomson, Thompson & Fine, 2005; Georges et al., 2008). Howcroft (2004) suggests early diagnosis can have a significant impact on caregivers, as it allows assess to medication, support services and benefits. Furthermore, a diagnosis may offer a sense of relief, in terms of an explanation for the changes they have witnessed in their CR. A diagnosis may also increase stress and a sense of denial for some caregivers (Howcroft, 2004). Providing support post-diagnosis is, therefore, important in supporting PwD and their families.

Secondly, it was noted that some organisations operated on a self-service basis, which might not have been helpful to some participants. Regular input seemed to have been favoured by the majority, allowing evolving needs to be tackled and the potential for risks to be addressed rapidly or even circumvented. Interestingly, it was identified that CR were more reluctant to engage in services than their caregivers. This was observed for several different reasons, including anxiety over permanently going into a nursing home or being in a state of confusion; or potentially that they feel safe and secure being looked after by someone that they are familiar and comfortable with (Marriott, 2009).

Thirdly, some caregivers expressed feelings of being disbelieved regarding their CR's behaviour, as well as impressions of being dismissed and patronised by services. This can potentially have a detrimental effect on their mental wellbeing, as well as generate a reluctance to use and trust services, creating barriers. This could lead to more individuals taking sole responsibility for the care of their loved one, without seeking aid. Many of the carers emphasised a desire to remain independent, without added commitments of external support services or that which was regarded as 'inferior' poor quality care. It is, therefore, not surprising that some families chose not to take up the offer of support services.

Overall, the views of the caregivers had significant implications for GP's and memory services, in that any lack of support for concerns and delays to obtaining a diagnosis was related to emotional consequences for the caregiver. Above all, the point was made that diagnosis was pivotal for caregivers in accessing support services, and this might be associated with an increased risk in anxiety and depression for the caregiver.

4.5.1.4. RQ4: From their experiences, what future interventions would caregivers suggest that would improve the support for those providing care to a family member with dementia?

Interviewees made several suggestions, based on their experiences of support services, for improvements. Firstly, most participants suggested being given more-in depth knowledge and understanding of dementia, which corresponds to previous literature, where caregivers sought more practical advice on help and more medical related information (Georges et al., 2008). This was recommended in line with having access to professionals on a one-to-one basis, for expert advice and guidance tailored to individual circumstances, rather than generic group support.

Secondly, the majority of participants stated a desire for more practical support. Some participants had accepted the use of domestic help as a means of lessening their responsibilities and eased the pressure of managing day-to-day stressors. The results of a study by Chong, Kwan, Chi, Lou and Leung (2014), suggested that domestic help may moderate the effect of stressors on the psychological distress of spousal caregivers.

Thirdly, caregivers expressed a desire for more respite to be available. Several suggested that it should be offered 'in-house', over a twenty-four-hour period, rather than within a care facility. Research suggests that availability of placements is limited, and care settings vary in provision and expertise for those with dementia (Georges et al., 2008; Hussein & Manthorpe, 2012; Lievesley, Crosby & Bowman, 2011); and domiciliary care provision is under-funded and has the least qualified staff in place (Davies, Maio, Vedavanam, Manthorpe, Vernooij-Dassen & Iliffe, 2014).

Finally, some participants advocated for access to psychotherapeutic interventions to be offered as an option on a regular basis, as a means to manage the high level of caregiver distress (Phillipson, et al., 2014). This indicates a need for participants to 'unburden' themselves and validate their experiences through an independent source.

Overall, the caregiver's evaluation of the support offered by various services, suggest what was wanted was in 'short supply', what was preferred was very limited and much of what was available did not meet the needs of the caregivers. At the same time, the caregivers are able to acknowledge the hindrances which get in the way of support and resources helping them, for which there are no ready-made solutions.

4.5.1.5. Group framework

A framework approach facilitated a case analysis within the themes (Ritchie & Spencer, 1994), that allowed the four groups identified from Phase I to be compared. This allowed caregiver's issues around psychological resilience and wellbeing to be captured.

The first theme, 'diagnosis facilitates support' was strongly related to the high resiliency groups. These groups were more likely to take action and instigate a process of investigation, rather than hesitate in seeking further clarification or require prompting before acting. The second theme, 'relentless deterioration' all groups expressed an increased dependence from the CR with little hope of improvement. Higher psychological resilience groups were better able to adjust positively to the increasing reliance placed upon them by their CR; whereas, those in the lower psychological resilience group expressed a greater sense of despondence on having to give up leisure and social pursuits.

The third theme, 'caught in the middle' was related most to wellbeing, especially those with low scores. Physical health difficulties of the caregivers impacted on their abilities to carry out care tasks. The fourth theme, 'unsustainability' highlighted some differences between psychological resilience and wellbeing groups. Higher psychological resilience groups were more likely to recognise their own limits and take action to 'fill in the gaps'; whereas low psychological resilience groups were more reluctant to relinquish their roles. Those participants with poorer health outcomes were more likely to request equipment, gadgets and aids to support them to carry out care tasks.

The fifth theme, 'adaptation, adjustment and effects of caregiving' was related strongly to those individuals with higher psychological resilience outcomes, this was also evident for the sixth theme, 'coping strategies'. More effort was made to protect time for themselves, 'me time', compared to those with lower psychological resilience scores. The seventh theme, ‘evaluation of support services’ all groups expressed concerns with regards to lack of consistency and continuity amongst service providers.

4.5.2. Limitations

There were several limitations to this phase of the study, which will be discussed in Chapter 5, Discussion.

4.6. Conclusion

The second phase of this study used a qualitative methodological approach to further illustrate the experiences of dementia caregivers in relation to their psychological resilience and wellbeing. Themes identified during analysis appear to support previous findings. Some interesting results have emerged from this interpretation of the data. Several recommendations could be extrapolated from the key aspects that have been interpreted from the findings. This will be discussed further in Chapter 5, Discussion (see Section 5.6.1. Recommendations).

Overall, the findings from this phase of the study provided a more in-depth view of the factors that play a part in the role of providing care to a loved one with dementia. There are some limitations to this phase of the study, therefore, findings should be interpreted with caution. General findings, practical implications for service development and an overall conclusion will be discussed further in Chapter 5, Discussion.

Chapter 5

Discussion

5.1. Introduction

The aim of this study was to highlight the lived experiences of dementia caregivers; focussing on the influence of psychological resilience as a mechanism to adapt and maintain their role as a care provider; and, to identify and examine their perspectives of current support services in meeting their needs. A mixed methodological approach was conducted in two phases, whereby Phase I informed Phase II. This allowed for a more comprehensive viewpoint, which took advantage of the strengths and specific values afforded by each method (Creswell, 2015).

In Phase I, a postal survey was conducted to gather information for a wide range of elements, including use and access of support services, psychological resilience and wellbeing. These outcomes were also used to select and recruit subjects for the second phase of this study.

In Phase II, a qualitative approach explored the lived experiences of caregivers, based upon their varying levels of psychological resilience and health status, which expanded and validated the findings of the quantitative postal survey. A qualitative interview was used as it is seen as, a "uniquely sensitive and powerful method for capturing the experiences and lived meanings of the subject's everyday world. Interviews allow the subjects to convey to others their situation from their own perspective and in their own words" (Kvale, 1996, p. 70).

5.2. An overview of the findings

Sub-hypotheses and research questions, for Phase I and II respectively, were formulated to reflect the proposed overarching research question for this study; which contributed to inform the outcomes of the research as a whole. Key points from the findings of the postal survey and interviews will be discussed below, in relation to overarching research questions outlined in Chapter 2, Systematic Review.

5.2.1. RQ1: To what extent does providing care impact on caregiver's ability to sustain and maintain their role?

The findings suggest that, overall, there were no specific factors that influenced how individuals undertook or modified their caregiving role. The data gathered from the postal survey and interviews highlighted that the experiences and circumstances of the participants varied. It is suggestive of caregivers needing to be flexible and adapt to the changing needs of their CRs as the condition progresses, which includes being able to accommodate their own individual circumstances, commitments and physical health difficulties.

The outcomes from the SF-36v2, in Phase I, suggests that providing care has a negative impact, mental wellbeing was reported as decreased for every respondent, with scores below the norm. This would suggest that the possibility of being a dementia caregiver may well diminish a person's mental wellbeing regardless of what is faced in the role. Furthermore, a decreased physical and mental wellbeing score was linked with higher risk of depression; the statistics suggested a one-in-two chance of a dementia caregivers developing a depressed state (as against the general population of a one-in-six chance).

The more mentally well the caregiver's perception, the more able they were to access support and resources. A decrease in physical wellbeing was associated with greater restriction on performing care tasks. This may suggest that physical and mental wellbeing is a crucial element that supports a caregiver's ability to perform their role. High resilient participants were more proactive in organising and planning support; these caregivers found ways of managing the demands on their capacity to care, resulting in possible lower risk of mental health issues and maintaining some form of quality of life. Individuals with low psychological resilience were more likely to relinquish their role.

From the findings in Phase II, the participants identified a range of coping strategies, which was also shown to reduce the negative impact of providing care in this sample. The research literature found that a greater range of coping techniques both known and used, by the caregiver, may potentially lessen the impact of caregiving on their mental health, which matches the outcomes of this study. The more strategies available for them to use, the less likely they are to develop symptoms of depression (Whittick, 1993), and thus, sustain and maintain their role for longer.

Interestingly, some differences were noted between spouses and ACC. Spousal caregivers expressed more losses and greater feelings of entrapment, than ACC, who felt they were ‘juggling’ other commitments. Research literature suggest that the relationship between caregivers who provide care to their spouse is distinct from others (O’Rourke, et al., 2010) and are identified as having higher risk factors when compared to adult children who are caregivers (Lee, et al., 2017; Sörensen, et al., 2002). This higher risk for spousal caregivers appears to be associated with their advanced age, and thus, they are found to be more susceptible to their own health problems, have lower incomes and form smaller social networks (Innes, et al., 2005; Meiland, Danse, Wendte, Klazinga & Gunnings-Schepers, 2001). These risk factors have also been shown to have a bearing on their emotional wellbeing and may determine their ability to be flexible and adapt in providing care (Senturk, et al., 2018). Plus, physical health may determine how much care they can safely provide (Holst & Edberg, 2011; Pot, 2004).

In general, participants acknowledged that their responsibilities increased, and their role was affected by the duration and frequency of care tasks. This appeared to become more pronounced as the condition of the CR progressed and they became increasingly dependent and reliant on their caregivers. The majority of participants seemed to agree that their role did change gradually over time. The length and duration of care has been shown to have a negative impact on physical and psychological measures (Kim, Chang, Rose & Kim, 2012). Moreover, the increasing level of dependence that the CR has on their caregiver has also been shown to be related to the risk of developing depression and this is exacerbated by the level of deterioration of dementia (RSAS & ADS, 2016). Overall, several factors were identified as impacting on the caregiver's ability to continue within their role.

5.2.2. RQ2: How does psychological resilience and wellbeing factors influence caregiver's awareness, access and use of available support services in order to provide care?

The results, from both phases, indicate that providing care is associated with reduced psychological wellbeing for both mental and physical functioning (HRQoL), although physical and mental outcomes may be affected to a different extent. Good mental wellbeing had a positive association with a range of support services used. This suggests having support to ease the burden of caregiving, may improve the wellbeing of caregivers (Markowitz, Gutterman, Sadik & Papadopoulos, 2003). Physical health was related to caregiver's ability to perform care tasks.

The more physically 'well' and able caregivers are the more likely they are to manage the more difficult care tasks, such as personal care and physical support to their CR. Caregivers with lower outcomes for psychological wellbeing, specifically physical health, are more likely to request practical aids to assist their caregiving role; although, mental health was more significant than the physical health component as an indicator for seeking and using a range of support services.

Individuals with higher psychological resilience appeared to have a greater awareness of their own needs and were more likely to 'take action' to protect their own wellbeing, such as seeking a diagnosis or accessing support services. This would suggest that more resilient individuals were more proactive and better able to manage stress and negative adversities, compared to those with low psychological resilience levels (McCabe & O'Connor, 2012).

Overall, the findings suggest that psychological resilience and wellbeing affect the awareness, access and use of available support services to a different extent. The physical health of caregivers may affect their ability and restrict the extent to which they can provide certain care tasks, as well as seeking practical aids to support them. Higher psychological resilience and mental wellbeing appear to allow a greater ability to cope with changing circumstances and seek support, rather than waiting for prompting or a crisis situation to develop.

5.2.3. RQ3: To what extent does awareness, access and use of available support services effect caregiver's ability to provide care?

The findings, in general, suggest that several factors may facilitate or hinder the caregiver's engagement with support services, including consistency and continuity of professional support organisations, other commitments and CR input. In Phase II, participants shared a varying range of support preferences and suggestions for future interventions.

In Phase I, caregivers reported that they felt support services were 'un-co-ordinated' or 'hidden', with many further indicating that they were unaware of support services. This could be related to the importance of having a definitive diagnosis that 'opens the door' to prospective services. This indicates that seeking support may be frustrating and time-consuming, whereas, services require a 'joined-up' approach to make it easier for caregivers to seek assistance and engage with services. Thereby, lessening the pressure on caregivers and promoting their ability to look after their CR within the community (NICE & SCIE, 2007; RSAS & ADS, 2016; Sörensen, et al., 2006).

Previous literature has found that the majority of caregivers do not use or access formal support services, or often report a lack of awareness or knowledge on support that is available (Vecchio, 2008). Caregivers may refuse such services for several reasons, namely that they might feel that it is inappropriate for the CR, they are managing at the time, support services are inaccessible or, they do not need external support (Brodaty, et al., 2005; Donnellan, et al., 2015; Innes, et al., 2005; Vecchio, 2008). This could be further exacerbated by the caregiver feeling that they are abandoning their CR or, that they are the only person capable of providing care to that person (Keeling, et al., 2008; Pulsford & Thompson, 2013; Vecchio, 2008; Watts & Teitelman, 2005). Innes, et al., (2005) pointed out that caregivers felt, even when support services were available, that the majority of services were unresponsive to their needs and the needs of their CR; "services need to develop which are welcomed by service users and which reflect their perceptions of their care needs" (p. 363).

The outcomes, from both phases, suggest that lone caregivers are more at risk for developing psychological distress. Having paid care or sharing care amongst family members or friends, participants were more likely to be able to leave the house, possibly to pursue leisure activities or work commitments, which appeared to have a positive effect. Providing an increasing amount and level of care over an uncertain period of time, increases the risk of social isolation, decreases the level of social activity and could potentially lead to economic deficits for the caregiver and wider family system (Hayley, 2003).

From the range of organisations and support services available in The Borough, The Admiral Nurses Services was indicated as the main service used, by more than 50% of cases. The majority of caregivers advocated for this service to be increased and resources made more available. Possibly due to Admiral Nurses being able to provide specialist knowledge, practical and clinical input, as well as one-to-one direct care for the PwD and their family (Dementia UK, 2015).

Overall, a limited conclusion can be drawn in regard to whether having an awareness, accessing and using support would have a positive impact on a caregiver's ability to provide care. The findings, however, do indicate the need for more consistency and co-ordination of services and a suggestion of having a single point of contact was made. Better signposting of services from the point of diagnosis was also highlighted as a requirement.

5.3. Reflexivity

It is acknowledged within qualitative methodology, that the researcher will make their interpretive framework explicit, which will shape their interpretation and inform their analysis, in order for them to reflect on the process (Coyle, 2007). As this study adopted a mixed methodological approach, it was felt that reflexivity should be applied to the whole research process, in order to "acknowledge the role of the researcher and it can increase the transparency of the research process" (Coyle, 2007, p. 18).

The main investigator (EDJ) had experience of working with individuals with dementia and family care providers prior to the conceptualisation of this study. Furthermore, they had a desired interest to pursue this area of working in future career options. It is possible, that previous knowledge and in-depth engagement with the research literature during the set-up of the project influenced the analytical process. Overall, the researcher aimed to minimise their influence throughout this study, especially during the collection and analysis of Phase II. As a Counselling Psychology trainee, they aimed to adopt the core concepts of their training, to endeavour to maintain a congruent approach, allowing caregivers and their responses to drive the data.

5.4. Strengths and weaknesses of current study

The mixed methodological design was a major strength of this study. Taken from the perspective of a phenomenological viewpoint, in which the aim is "to achieve an authentic and comprehensive description of the way in which a phenomenon is experienced by a person or group of people" (McLeod, 1996, p. 70), this provided a multi-perspective approach. The integration of both quantitative and qualitative data allowed an interpretation of the findings, based on the combined strengths of two sets of data to understand the research objective (Creswell, 2015).

Furthermore, this study was the first to integrate psychological resilience and wellbeing (HRQoL), and their effects on seeking and using support services by dementia caregivers, especially with a UK sample. A rich data set of information has been obtained through this study, which may afford additional opportunities for further analysis; however, this is beyond the scope of the current research study.

5.4.1. Limitations

The findings presented in this study make generalisability difficult, due to limitations in several areas, including the recruitment of a relatively small, non-representative, convenience sample. Firstly, participants may not be representative of all dementia caregivers as the research was conducted in one geographical area, The Borough, and were recruited through the Admiral Nurses Service. Secondly, due to sampling from one location this may not be demonstrative of services available in other areas, including availability of funding, support services and speciality of staff.

Thirdly, only individuals known to services were included in this study, which is a further limitation, as the views and opinions of caregivers not known to services have not been considered. Fourthly, the extent of physical health symptoms reported were not examined as to their long-standing nature, it is therefore, unclear how physical health was affected before and during their role as care providers. Similarly, previous mental health difficulties were not explored. Fifthly, the majority of the sample were White British, therefore, generalisability to other cultural and ethnic background may be difficult. Finally, a cross-sectional design was used, rather than a longitudinal design.

Further limitations specific to each phase are presented below.

5.4.1.1. Sample size

5.4.1.1.1. Phase I

Due to the small sample size recruited, a low statistical power was achieved. A recommended level for statistical power in psychological research is 0.80 (Cohen, 1988); however, for this study a post-hoc analysis calculated a power of 0.33. Low power increases the likelihood of making a type II error, in which a genuine effect could be missed. This means that, although a medium effect size was calculated, the results should be interpreted with caution.

5.4.1.1.2. Phase II

Compared to the other groups, only one participant was allocated to Group 2. This may have limited the interpretative value of these findings.

5.4.1.2. Postal survey

Vaux and Briggs (2006) argue against the use of a postal survey when data collection is urgent, has numerous open-ended questions or an elaborate system of contingent questions. The number and type of questions could have contributed to the lack of responses to the postal survey. Participants may have felt vulnerable when answering certain questions, or simply, that they did not have time, or as with other participants, their CR had either moved into a care home or had passed away. Postal surveys, however, according to Edwards et al. (2002), are a financially viable mean to gather data from large, geographically dispersed populations.

Section one of the survey was related to socio-demographic questions and were based on relevant literature and predictors of caregiver stress and burden. This aspect of the postal survey was not piloted and the reliability and dimensionality (exploratory factor analysis) of the scale was not measured (Brace, Kemp & Snelgar, 2009; Coolican, 2004). Time-constraints and limited access to the sample were barriers to this, more robust, methodological approach.

The SF-36v2 comprised the second section of the survey. It is possible that the age of participants and a high number of reported physical health difficulties could have affected the results. The mean age of participants were 67 years and the majority reported a difficulty relating to the musculoskeletal and nervous system (40%). Therefore, scores on the physical health component may be lower than expected, even when controlling for the effect of providing care.

The third section comprised the PRM (Windle et al., 2008), which was used to measure psychological resilience. The PRM was chosen, as its purpose is to assess psychological resilience that acts as a protective factor against risks and adversities (Windle, et al., 2011). It has also been used in the UK with older adults, aged fifty and over; and the previous subscales have been used with adolescents (Windle et al., 2011). Its use specifically for dementia research is currently limited, and therefore, difficult to compare the findings to other studies that have used different measures of psychological resilience (Gooding, Hurst, Johnson & Tarrier, 2012).

5.4.1.2.1. Response rate and missing data

The response rate for the postal survey was lower than anticipated (33.7%), which reduces the effective sample size and can introduce bias (Edwards et al., 2002). This is further exacerbated by missing data. No follow-up reminders were sent out to caregivers, which may also account for the low return rate (Ashley & Kleinpeter, 2002).

5.4.1.2.2. Self-report bias

Phase I relied on self-report measures, which may be at risk of self-report bias. There was a possibility that participants did not give an accurate report in regard to their psychological wellbeing or level of psychological resilience. Previous studies have shown that people are more likely to report positively and, therefore, create bias (Cucciare, et al., 2010; Knight & McCallum, 1998).

5.4.1.3. Semi-structured interviews

There was a gap of eight months between the survey being conducted and the first interview taking place. Within this period of time, the views and situations of some caregivers many have changed, with some using hindsight to reflect and process the part they played; whereas, others might still be ‘immersed’ in the situation and have a different outlook on their situation. It can be argued, however, that lived experiences of dementia is idiosyncratic and most individuals will experience a different journey, even if some similarities are shared.

5.4.1.3.1. Phase II analysis process

It is acknowledged within qualitative research that the researcher may have an influence on the interpretation and, therefore, the validity and reliability of the outcomes. As Patton observes,

> “qualitative analysis transforms data into findings. No formula exists for that transformation. Guidance yes. But no recipe. Direction can and will be offered, but the final destination remains unique for each enquirer, known only when – and if – arrived at” (2002, p. 432; cited in Coolican, 2014, p. 306).

5.5. Research implications

The use of research to create knowledge and define practices are interrelated, "research is an activity that generates knowledge and so it is a conduit between practice, knowledge and society. At various points it describes, challenges, critiques and explains social and health policy and practice" (Clarke, 2001, p. 96). In order to promote service development founded on evidence-based practice, a robust research platform is essential.

Future studies may focus on recruiting participants that are not known to services. It should be noted that according to the Alzheimer's Research UK (2019), only 66% of PwD in the UK receive a diagnosis. This could indicate that a proportion of the population is under-represented and that a group of caregivers are not being targeted, that potentially require support. Moreover, this sample could be invaluable in providing successful and positive outcomes for providing care to PwD. It may be useful to include the perspectives from professionals and services, to incorporate their views on services offered to dementia caregivers (Joling, et al., 2017).

The majority of dementia research has focussed on the efficacy of reducing CB (Keeling, et al., 2008; Sanders, et al., 2008); however, little research has been conducted on structured, specific interventions for caregivers, "… much of the time we are not yet justified in saying, 'This technique has been shown to be the most likely to be effective with this kind of problem and for someone with these characteristics.' Rather, it is a matter of discussing options, perhaps modifying one or more of them, and then undertaking individual experimentation and follow-up" (Bayne, 2012, p. 651). A pilot study by McKinnon et al. (2013) focussed on teaching caregivers problem-solving strategies, within a structured intervention programme. This indicated that tailored individual interventions for informal caregivers are being considered; however further research is required to assess the effectiveness of such an intervention compared with the current provision of information, advice and support (RSAS & ADS, 2016).

Some interesting findings were identified within this study, which would benefit from further research being conducted. This includes: exploring the extent of the physical health difficulties of caregivers further and how these may impact on their ability to carry out their caregiving tasks, over a longer period (longitudinal design), rather than at only one point in time; the ability for caregivers to leave the house appeared to provide some respite and supported better wellbeing outcomes, this may provide an interesting element to explore; and finally, incorporating the viewpoint of CR's on accessing and using available support services, as well as their reluctance to engage, would also be valuable to explore in future research (Phillipson, et al., 2013).

5.6. Clinical implications

Research outcomes seem to take into consideration that dementia care requires a more person-centred perspective as advocated by Kitwood (1999), which would take into account the dynamic and systemic relationships around family members who provide care, as well as broader cultural and societal perspectives. It seems, however, that research findings do not always pass onto organisations that develop and design interventions to support dementia caregivers. As Clarke states, "doing research and using research is not linear" (2001, p. 96).

5.6.1. Recommendations

From the key aspects that have emerged from the findings of both phases of this study, has come reflections on the 'fit' between the support needed and the actual types of interventions offered (Cuijpers, Hosman & Munnichs, 1997). Overall, caregivers expressed a sense of obligation, responsibility and duty to look after their CR, however, the majority stated a desire to continue in their role despite negative outcomes (Putnam, et al., 2010). Furthermore, they desired to remain independent, with the acknowledgement that this could not continue (Kraijo, et al., 2015). It is, therefore, important to consider individual circumstances when offering support as each PwD and their families may have different needs, wishes and viewpoints.

Two main areas have been considered with corresponding ideas for potential recommendations to inform future service development and social policy; these are presented below.

5.6.1.1. Support service provision

Several issues have been highlighted by caregivers in this study in relation to professional services.

5.6.1.1.1. Consistency and continuity

The main element highlighted by participants was consistency and continuity by services and professionals. Miesen (2006) suggests that continuity is a primary requirement in the relationship between professional services and families with dementia, in order to understand how caregivers cope with the condition of dementia. Having regular input from one or two people, such as an Admiral Nurse, was suggested, alongside face-to-face contact. Even if regular contact is not required, for example, some caregivers may be managing at the time, intermittent follow-ups were suggested, as some caregivers felt very negatively about ‘self-service’, i.e. contacting services once they were known.

5.6.1.1.2. Dementia envoy

Participants expressed a sense that support services were ‘un-co-ordinated’ and ‘hidden’, many advocating for one point of access to approach for knowledge and types of services available. One suggestion is that of a dementia ‘envoy’ to be piloted, who could provide a link to all services and act as an informant and signposting to appropriate services. This liaison may possibly be housed within the Admiral Nurses Service. Another suggestion would be for a greater joining up of health and social services to promote co-ordination of support, advice and guidance to the PwD and their families.

5.6.1.1.3. GP 'gateway'

The GP was reported to be the main point of contact for most participants, which allowed onward referral for gaining a diagnosis, and ultimately access to further support mechanisms. Therefore, GPs are valuable in terms of being a 'gateway' to diagnosis and support. GPs should, thus, be provided with clear pathways and referral options to aid the process to specialist services in order to aid early diagnosis and access to support mechanisms. Further training and supervision should also be offered to enhance their skills.

5.6.1.1.4. Screening

This research study has highlighted the value of identifying caregivers with low psychological resilience, as they are more likely to be at risk of psychological distress. It is proposed that psychological resilience measures can be used to identify at risk caregivers, in order to encourage and develop psychological wellbeing, as well as to divert distress and risky health behaviours (O'Rourke et al., 2010). This can be incorporated in an assessment process, which may also benefit from including regular screening of psychological wellbeing, physical and mental health functioning, due to the increased risk of developing difficulties as the CR deteriorates (Wennberg, Dye, Streetman-Loy & Pham, 2015).

A clear pathway for regular screening could be established from point of diagnosis, with follow-up screening periodically at different stages (Kršiková & Zeleníková, 2018; Välimäki, et al., 2009). This could be facilitated through contact established through the

Admiral Nurses Service or the 'dementia envoy', with regular reviews and follow-ups, as mentioned above.

5.6.1.1.5. Community-based support

The main source of support requested by caregivers in this study was access to residential respite. Availability, however, may be reliant on funding and provision of resources. In-home respite and more access to practical support resources, such as domestic help, was suggested by caregivers them to support caregivers to deal more effectively with their caring duties.

5.6.1.1.6. Practical aids

The findings suggest that caregivers who report lower psychological wellbeing, especially in terms of their physical health, have a greater need to use practical aids and 'gadgets' in order to fulfil their caregiving duties. Regular reviews and assessment of practical needs should be undertaken, which could be incorporated alongside the regular screening element, as proposed above. A possible 'library' of equipment could be made available, whereby necessary and appropriate equipment are 'rented' out to meet the current needs of caregivers and the PwD, for example wheelchairs.

5.6.1.1.7. Memory testing

Several participants noted the difficulties around continuous memory testing and indicated the increased levels of anxiety and distress experienced through this process (Akintomide & Fazil, 2017; Rosness, Ulstein & Engedal, 2009). A clear pathway for use of memory-screening tests should be developed, including reducing how often tests are used and working with the PwD and their families collaboratively to ease anxiety around testing (Akintomide & Fazil, 2017).

5.6.1.2. Support service interventions

It is recognised that successful interventions should be designed to address the development of coping strategies, enhance psychological resilience and should be tailored to the needs of the caregivers (RSAS & ADS, 2016).

5.6.1.2.1. Group intervention compatibility

Most of the participants favoured a one-to-one approach, rather than group interventions, which would support the findings for a consistent and continual approach, as outlined above. Assessing individuals for compatibility may reduce 'drop-out' rates in group interventions, such as psychoeducational groups, and facilitate caregivers' preferences.

5.6.1.2.2. 'Talking therapies'

It is important to acknowledge one-to-one therapeutic interventions, in contrast to general group or management programmes, as they are limited in their effectiveness for people whose troubles stem from individual conflicts or personal agendas that these programmes do not address (Lazarus and Folkman, 1984). Furthermore, psychotherapy may support caregivers with the explicit grieving which is needed to cope (Zarit & Edwards, 2008). Offering psychotherapeutic interventions and more access to psychological input is, therefore, recommended as a frontline measure, rather than as a last resort.

Presently, there is limited literature on dementia caregivers and the use of talking therapies. In general, it appears that it is more openly accepted for mental health and cancer caregivers to have access to talking therapies (Mind, 2014). The carer's strategy 'Recognised, valued and supported' (HM Government, 2010) mentions that those caregivers who are known to have symptoms of anxiety and depression should have access to NICE guideline treatments for depression and anxiety (2009); especially as those are known difficulties faced by dementia caregivers.

5.6.1.2.3. Resilience-building training programmes

The findings suggest that higher resilient individuals are more likely to engage in self-care and utilise available resources, than those with low psychological resilience. It is, therefore, important to foster psychological resilience in caregivers. One recommendation would be a psychological resilience training programme that could be developed and offered to those who provide dementia care to a family member. The Penn Resilience Programme, for example, is aimed at developing skills that empower individuals to be more resilient in dealing with adverse situations (Gillham, Reivich & Jaycox, 2008; cited in Reivich & Seligman, 2011). Originally developed for teachers and college students, it was further adapted for the American Army for help with record rates of suicide, depression and post-traumatic stress disorder, emphasising prevention and positive psychology (Bayne, 2012).

Currently, limited interventions exist that specifically address the building of psychological resilience, especially for dementia caregivers (Petriwskyj, Parker, O'Dwyer, Moyle & Nucifora, 2016). A review by Petriwsky, et al. (2016) only identified two interventions and these had limited success. This, however, could be related to "small sample sizes, methodological flaws and a lack of consensus on the definition and measurement of resilience" as reported by the authors (Petriwsky, et al., 2016, p. 252).

5.7. Implications for Counselling Psychology

Kitwood suggests that dementia care "requires a very high level of personal and moral development on the part of those who undertake it. There can be no question of bolting on a body of knowledge, or of imparting a set of skills in a semi-automated fashion. We are looking for very intelligent and flexible action from a 'reflexive practitioner'" (Kitwood, 1999, p. 130-131). Methods of education and inconsistent support mechanisms to date, seem inadequate as just “bolting on” knowledge (Kitwood, 1999, p. 130). The current framework of working needs to be reconsidered, in order to develop more psychologically able and ‘reflexive’ caregivers.

This new culture should emphasise the development of the experiential self, in order for the person to engage in effective caregiving. This involves developing self-knowledge within the world of feeling and emotion and being willing to bear the burden that arises from attachment; this will allow the carer to manage their feelings of being overwhelmed by their emotions (Baldwin and Capstick, 2007). If family caregivers are well supported this is possible (Coates, 1995).

Psychology, and Counselling Psychology especially, may be well placed to undertake this role. Counselling Psychology advocates collaboration between the therapist and the client, in order to understand their inner world and construction of reality through their subjective experiences (Strawbridge & Woolfe, 2010). Further application to Counselling Psychology may include; an understanding from a life course perspective (Chambers, Allan, Phillipson & Ray, 2009), support to process grief and bereavement (Miesen, 1997; Zarit & Edwards, 2008), family systems and dynamic relationships, attachment and roles (Kitwood, 1999).

Counselling Psychologists would be able to lead on the promotion of psychological resilience and wellbeing of caregivers through specific psychotherapeutic interventions and strategies that are theory-based (Fava & Tomba, 2009). Thus, efforts could be targeted not just by “alleviating the negative (psychological distress) through psychological interventions […] Engendering the positive (through the promotion of psychological wellbeing) could be another way to reach the same goal, and may yield important protective factors” (Caffo, Belaise & Forresi, 2008, p. 332-333). Examples include, wellbeing therapy (Fava, 1999; Fava & Tomba, 2009), mindfulness-based interventions to help reframe burden (Weisman de Mamani, et al.,

2018) and psychological resilience-focused interventions (Gulin, et al., 2018; Petriwskyj, et al., 2016).

Furthermore, they would be able to support health professionals in terms of training, supervision and development. Updating practice and supporting professionals to better understand and recognise psychological resilience and its determinants in caregivers, could enhance the capacity for accurate identification of caregivers with lower psychological resilience (Cherry et al., 2013). This will allow for more timely and appropriate support interventions to be put in place, especially for those caregivers who are more vulnerable and at risk of burden (Joling, et al., 2017).

5.8. Conclusion

This study provided further insight into the lived experiences of dementia caregivers and contributes to existing literature. Despite the limitations of this study, the findings suggest that an association exists between psychological resilience and wellbeing, and that this impacts on the access and use of support services. It is hoped that these findings have shown the benefit of incorporating psychological resilience as a useful mechanism to aid current and future debates regarding goals, outcomes and interventions to support those who look after a PwD (Nolan, Ingram & Watson, 2003).

Understanding a caregiver's capacity to adapt, despite ongoing increased difficulties as the condition progresses, will allow support services to target their interventions to those at a high risk of psychological distress. This will also allow services to tailor aid, that promotes the emotional, social, and mental wellbeing of dementia caregivers. Professional and support services, however, cannot be standardised and must be adjusted to the individual circumstances and situation (Duijnstee, 1993). This research study highlights services that work well, areas that can be improved and contributes overall, to the growing understanding of the lived experiences of providing care to a family member with dementia.

Counselling Psychology may have an important role to play in advocating a person-centred approach that allows the needs of the caregivers to be met within a holistic dementia care framework, which takes into consideration all those affected by dementia. As well as the use of theory-based wellbeing and resilient approaches that emphasise positive mental wellbeing, rather than focussing on negative affective symptoms.

In conclusion, the findings in this study could be used to develop and inform intervention programmes that promote and enhance positive aspects of caregivers' adaptive processes, such as their psychological resilience. Thereby, supporting dementia caregivers to maintain their roles longer, improving the quality of care they provide and sustaining their ability to look after their loved one within the community (Cherry et al,, 2013; Dickinson et al., 2017; Gulin et al., 2018; NICE & SCIE, 2007; Petriwskyj et al., 2016; RSAS & ADS, 2016; Sörensen et al., 2006).

Chapter 6

Critical Appraisal

This chapter aims to provide a critical appraisal of my development as a scientist-practitioner and the value of my contribution to research within clinical practice. I hope to give an outline of my research journey from conception to eventual conclusion.

I have always been interested in dementia. This may seem odd at first, although one of the many things that attracted me to psychology was how the mind shapes and potentially determines behaviour. I suppose you could say as a psychologist, dementia (in all its varying forms) is the epitome to study the human mind and how it functions. It fascinated me, how one condition, disease, can have such a monumental effect on a person. It was only after I worked as a domiciliary caregiver that I realised not only did it affect the person, it had universal repercussions for all known to that person. It puts me in mind of throwing a pebble into a pond and watching the ripples, growing larger and wider.

Hence why I chose to focus my research thesis on dementia caregivers. As I have always had an interest in dementia, subsequently I have always wanted to work with older adults. I cannot say with utmost certainty why this is, I just do. It is not surprising then, that throughout my training course I have steered towards this specialism. So, not only did I choose an area that I had particular interest in; secondly, it was also geared towards an area that I would like my career path to follow. With this in mind, therefore, many of my academic pursuits during my training bore in mind this particular topic. Thirdly, I also wanted to make a difference. I wanted to research a topic in an area that I felt would be of use. Having completed a dissertation for my undergraduate psychology and master's degree, both of which are stuck somewhere on a shelf, in a cupboard, I did not want the same fate for my research thesis.

At the time of deciding on my research topic, I was also fortunate enough to be introduced to the 'Commissioner of Special Projects' in Telford and Wrekin Council, through the domiciliary care agency that I was working for. This led to being put in contact with the 'Commissioner for Carers' and subsequently, the Admiral Nurse's Service. Here was an opportunity to work with services and produce something worthwhile that might make a difference.

My motivation, therefore, to target dementia caregivers in Telford and Wrekin was admittedly one of convenience. Not only did I live there, the contacts that I was able to make offered the potential to make a difference to the everyday lives of family caregivers, even if it was just one area. Once my thesis is complete, I am hoping to meet with Telford and Wrekin Council to discuss the outcomes of the research project and potential recommendations. Although the study was focused on one area in the UK, if the council chooses to act on any recommendations and make changes, this may potentially have a wider impact throughout the country. Even a small change may make the biggest difference to someone. Again, I am reminded of ripples in a pond. And as an ancient Chinese philosopher once noted, a journey of a thousand miles begins with just one single step (Lau Tzu, 6th Century).

I knew the area that I wanted to research; it was just a case of narrowing down what it would look like. As I was discussing potential areas and topics to research with my academic supervisors, I was introduced to the concept of psychological resilience through reading an article suggested by a tutor. It was as if a light bulb had turned on. This led me to look at psychological resilience in relation to dementia caregivers.

I think the concept of psychological resilience struck a personal chord with me. Throughout my doctorate, I experienced personal difficulties, emotional struggles and academic setbacks. Throughout this journey with each bump in the road, twist and turn, I managed to endeavour, to show myself that I have the capacity to recover. I discovered that I was resilient. Personally, psychological resilience became an important aspect that I wanted to incorporate into my overall journey of self-awareness and apply to my professional practice.

I admit that I did not go into psychology for research or statistics (they like keeping that one a secret, how naive I was). In my clinical practice, however, I have learnt that research is important. Evidence-based practice is necessary. Conducting this particular research project has provided me with a newfound appreciation for carrying out and doing research. It is not something that I have felt previously. Perhaps having chosen an area that I am passionate about allowed a greater appreciation of how doing research can potentially improve practice and develop support services. I chose to do a mixed method approach, because I felt that I wanted to challenge myself and also give myself the opportunity to become more confident in quantitative and qualitative research methods.

With the prominence to rely on research and show the use of evidence-based practice, it was important for me to be able to show my professional competency in being familiar with both a qualitative and quantitative approach. As Kvale suggests “qualitative and quantitative methods are tools, and their utility depends on their power to bear upon the research questions asked. As tools they require different competencies …” (1996, p. 69). As a Counselling Psychologist, this adds to our identification of being a scientist-practitioner, suggesting an “engagement in research and the role of the practitioner as producer, as well as user, of knowledge and understanding” (Strawbridge & Woolfe, 2010, p. 6).

Unfortunately, I had some delays with obtaining ethical approval from the University. This had a subsequent knock-on effect of gaining ethical approval from the Council, as one was reliant on the endorsement of the other. This process took several months, including having to change one of the validated questionnaires that I proposed to use. I found this process upsetting and somewhat defeating. Eventually, I was granted approval from the Ethics board, which allowed the ball to start rolling to apply for permission from the council to continue. Then I had to wait for the printing of the survey pack to be completed. Again, it all felt like delay upon delay. Eventually the postal questionnaire was sent out. When the first few returned, there was a certain rush of excitement.

Again, I will be honest and admit that statistics is not my strong suit. I struggled. It did not help that there was a vast amount of information to collate, analyse and make sense of. It took me several months to get my head around some of the processes and procedures for analysing surveys. There were times where I wanted to throw the computer out the window and SPSS most definitely was not my friend. But I persevered and now I can say with pride that I managed, and I got through. Previous and current peers gave a warning that your research thesis will consume you and that you may develop a love-hate relationship. In hindsight, I can appreciate that sentiment and for the most part it is true. Also, few people seem to understand the all-consuming nature of writing a thesis unless they have undergone something similar. On reflection, I can relate this to some of the struggles that caregivers experience or even individuals with an illness or condition that is distressing or disabling.

I also had help. Peers, colleagues and supervisors were invaluable. Especially one peer who became my statistics ‘guru’, it helped that I could just reflect SPSS jargon and statistics procedures and she was able to speak the same language, even help me interpret at times. Again, throughout my journey on the doctorate, the priceless support offered by friends and family cannot be quantified. They provided that precious outlet and kept me focussed and through them I became more resilient.

Once the survey was analysed and I had sufficient data to support a second ethical application, I re-applied to the board for the second phase of my study, semi-structured interviews. As my first experience was far from positive, I did not look forward to going through this process again. Thankfully, the process was a little more straightforward, with a few tweaks, I was off. With the interviews, there was a little more of a personal element to it. The survey felt a little more impersonal, therefore, when conducting the interviews, I felt privileged that these individuals would take time to share their subjective experiences with me. At first, I felt nervous about conducting the interviews, however all the participants were so forthcoming and engaging. Many related that they wanted to 'give back' in a sense, share what had helped them, in order to help others. I was conscious that this allowed them the first potential opportunity to reflect on their caregiving careers and how this has impacted on them and the losses sustained throughout their journeys.

What struck me the most after the interviews, was that each person had a different experience of services, from getting a diagnosis to achieving respite care. I believe this came through when analysing the responses and overall, a sense of unrelenting decline was for me the strongest theme. From my 'field notes' taken after each interview; an unsustainable element was also interpreted. This also came through in the analysis of the interviews. Having looked after and cared for a loved one, as well as being a paid carer, I could relate to these struggles of feeling entrapped by my responsibilities and feeling 'stuck in the middle'. I also found something to admire in the few caregivers that I was privileged enough to meet, their ability to keep moving forward even as their world seem to get smaller and smaller.

Due to difficult personal circumstances and delays through gaining approval from the ethics board, amongst other things, my thesis has taken longer than expected to complete. Not that this was unusual, several of my peers were also delayed. Although I had essentially finished the three-year training course, my thesis component was still outstanding, and I was more or less at the beginning stages of gathering the data. My supervisors and tutors were extremely supportive, and I will be eternally grateful for that. Difficulties arose for me when

I required an extension and expressly stated that I did not wish for a 'leave of absence'. I know that I work well to deadlines and require that perceived pressure to work, having a suspension would not be conducive to this. Unfortunately, rather than an extension I was granted a ten month leave of absence. As I suspected, this was not useful for my psychological frame of mind and I slightly went off track, with no incentive to produce work. I did take the time to conduct and complete all my interviews for the second phase of my study. It was at that time, that I also applied and was successfully granted a full-time post.

This led to, what I believe, the unusual situation of working full-time whilst trying to complete the write-up of the thesis. I found this extremely difficult, trying to juggle all the elements including my personal and social life. As time progressed, my social life diminished and my personal life along with it. Almost as if operating on a skeleton crew. On reflection, some of the participants I interviewed expressed this sense of 'juggling' and I can appreciate some of the difficulties that they encounter, such as, feeling entrapped and encumbered. For me, at least there is an end in sight.

When undertaking a mixed method approach, I did underestimate the time it would take for the analysis and subsequent write-up. I also found it difficult to condense the amount of information that has been gathered in this study. Working full-time and having only so much annual leave to take, it was difficult to manage, especially having to give up weekends and missing out on certain things. It has been worth it though, I am proud of what I have achieved. Working within a similar area has also given me further insight into clinical working and how my research could be applicable and support the development of services.

6.1. Conclusion

The original aim of my research was to highlight what works, what needs to improve and what needs to be done differently. Very ambitious, I know. Through the development and changes that my research project has undergone, my main thought was to identify possible developments in order to provide appropriate support. There is a very real possibility that as the population ages and incidences of dementia increase, psychology services and applied psychologists will be more likely to encounter this client group.

Throughout the last several years, whilst attempting to prepare for this research project and eventual thesis, it has occurred to me that many of the research findings are similar to those of the 1980s and 1990s when research on dementia and dementia caregivers bore fruition. As I have conducted this study and tried to bolster my own knowledge and understanding, it seems that 20 and 30 years on we are still investigating and confirming the same underlying issues. Perhaps, yes, with new terms and modern outlooks, the fact remains, however, that dementia caregivers are at high risk. Family caregivers are recognised as a group that are vulnerable and at an increased risk of psychosocial distress and risky health behaviours. What I find incredible is, that although this is known, little support is put forth in terms of psychological wellbeing. Counselling and psychotherapeutic intervention are almost provided as a last resort, rather than a first-line defence. What I have hopefully highlighted is that psychological intervention is necessary and from my training and knowledge, Counselling Psychologists will be best placed to support these familial caregivers. As scientist-practitioners we are at the forefront to identify, examine and instigate potential developments in guidance and practice. Counselling Psychology, with its underpinnings in humanistic and phenomenological approaches, aims to facilitate the client’s own resourcefulness and their promotion of growth, through the engagement of subjective experiences and beliefs.

Fava and Tomba (2009) state that the “underlying assumption of psychological therapies (whether pharmacological or psychotherapeutic) is to restore premorbid functioning”. This is similar to the concept of psychological resilience, to ‘bounce back to a previous state’; although, as decades of research has shown, the ability of human beings is remarkable and exceptional. Defining psychological resilience is, and has been challenging, for the reasons I believe are, that it is a multifaceted concept. It is dependent on the complex interplay of the social, cultural, biological, psychological and historical context of an individual. It is, therefore, difficult to pin down exactly what psychological resilience is and how it is made up and works for each individual. Psychological resilience may need to be reactivated in some and for others, it may need to be introduced and built on.

Wanting to make a difference and empowering others lies at the core of what being a Counselling Psychologist is. My own life journey has helped shaped that and within that my own experiences of being cared for and providing care.

Rough estimated word count: 35,000 (excl. tables, diagrams, quotes and references).

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