# Surviving or Thriving: Resilience in informal carers of people with dementia

**Susan May Jones**

**School of Health Sciences**

**University of East Anglia**

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# DECLARATION

No part of this thesis has been submitted for any other degree or qualification at this or any other University.

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# COLLABORATORS AND CONTRIBUTORS

SJ was primarily responsible for the conception and design of the studies in this thesis. Prof. Eneida Mioshi (primary supervisor) and Dr. Anne Killett (secondary supervisor) provided direction in conception and design.

SJ was responsible for data collection, data analysis, data interpretation and drafting of all chapters. Additional statistical support and oversight for chapter 8 was provided by Dr. Michael Woodward. Qualitative data analysis (chapters 5 and 9) was supported by Bridget Veldhuis.

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# ABSTRACT

Background: Providing care for a friend or relative with dementia can be stressful. Dementia carers are at greater risk of developing mental health problems than other carers or the general population. However, not all carers experience distress; caring can also be a positive experience. Resilience has been identified as the defining characteristic between carers who are merely surviving and those who are thriving.

Aims: This study aimed to explore resilience in carers of people with dementia.

Methods: A two-phase sequential mixed-methods approach was used. Phase one employed quantitative methods to investigate the relationships between resilient coping, subjective wellbeing, and social support. In phase two, qualitative methods were used to understand carers' conceptualisations of resilience and to identify the resilient coping strategies carers used to overcome care-related challenges.

Results: Phase one results showed that highly resilient carers report less psychological distress. Resilient coping was a partial mediator in the distress-wellbeing relationship. Attending a Dementia Café was positively associated with higher resilient coping and subjective wellbeing, although no causal relationship could be identified from the data. Investigations of social support showed that all four domains of support (emotional/informational support, affection, tangible support, and positive social interaction) had a positive relationship with resilient coping but no single domain had greater influence on resilience overall.

Phase two findings revealed that carers' conceptualisations of resilience align with definitions found in the literature but carers place greater emphasis on self-compassion and the fluctuating nature of resilience. Highly resilient carers used strategies that maintained their self-identity, and supported them to engage with support networks, e.g. Dementia Cafés, and navigate formal care services.

Conclusion: Together, these findings emphasise the importance of resilient coping in promoting carer wellbeing. Health and social care providers should design and deliver personalised services that support carers to develop and maintain resilient coping strategies, which help them to achieve their caring goals.

# CONTENTS

# LIST OF TABLES

# LIST OF FIGURES

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Hey girls! Mama’s done; shall we go climbing?

# 1 INTRODUCTION

## 1.1 Introduction

There is a growing interest in resilience and its role in supporting people to live well and overcome adversity. The Care Act 2014 defines carers as individuals who provide help and support to an adult who cannot care for themselves (HM Government, 2014). The role is essentially unpaid, and care may be provided for a friend or family member who due to illness, frailty, disability, a mental health problem or an addiction cannot cope without support (Carers Trust 2019). Those who provide care for a person with dementia are known to be at risk of psychological distress, poor physical health, financial strain and social isolation (Alzheimer's Research UK, 2015).  Therefore, understanding the factors that influence whether an individual ‘thrives’ or merely ‘survives’ in their caring role is an important area for research and clinical practice. Resilience refers to the capacity to adapt and ‘bounce back’ from adversity without experiencing lasting psychopathology (Rutter, 2012). Resilience was chosen as the focus for the thesis because higher levels of resilience have been linked to improved outcomes for individuals, while low resilience is associated with negative consequences and ongoing difficulties (O'Rourke, et al. 2010).

## 1.2 Structure of the thesis

The overall structure of the thesis is shown in Figure 1-1. Chapter one provides a general introduction to the thesis.

Chapter 2 first provides contextual information about dementia and then provides a background of relevant literature related to resilience in friends and family members who provide care and support to a person with dementia. This section concludes with an overview of the main research questions.

Chapter 3 gives an overview of methods, including details about ethical approvals, participant recruitment and the development of the survey and interview schedule.

Chapter 4 gives details of the participants and the people with dementia they cared for.

Chapters 5-9 explore resilience in caring through five research questions, using a two-phase sequential mixed-methods approach (Figure 1-1). Phase one used a quantitative approach. Adults providing care for a friend or family member with dementia completed a cross-sectional survey comprising standardised measures of resilience, wellbeing, social support, affect and burden. The first analysis focused on resilient coping and how it can support carer wellbeing (Chapter 6). The following analyses examined social support and resilience. In particular, carers' use of Dementia Cafés (Chapter 7) as a social support setting was examined. An investigation of different types of social support (emotional/informational, affection, tangible support, and positive social interaction) and their relationships with resilient coping was then conducted (Chapter 8).

Building on these findings, in phase two, semi-structured interviews were used as the primary data collection method. Chapter 5 explored carers' conceptualisations of resilience. Chapter 9 examined the resilient coping strategies carers used to overcome the key challenges associated with looking after a person with dementia.

Lastly, Chapter 10 forms the general discussion. It presents a summary of the findings for each analysis and provides a synthesis of findings across the research questions. The overall strengths and limitations of the programme of research are discussed. Implications for theory, policy and practice are examined and suggestions for future research made.

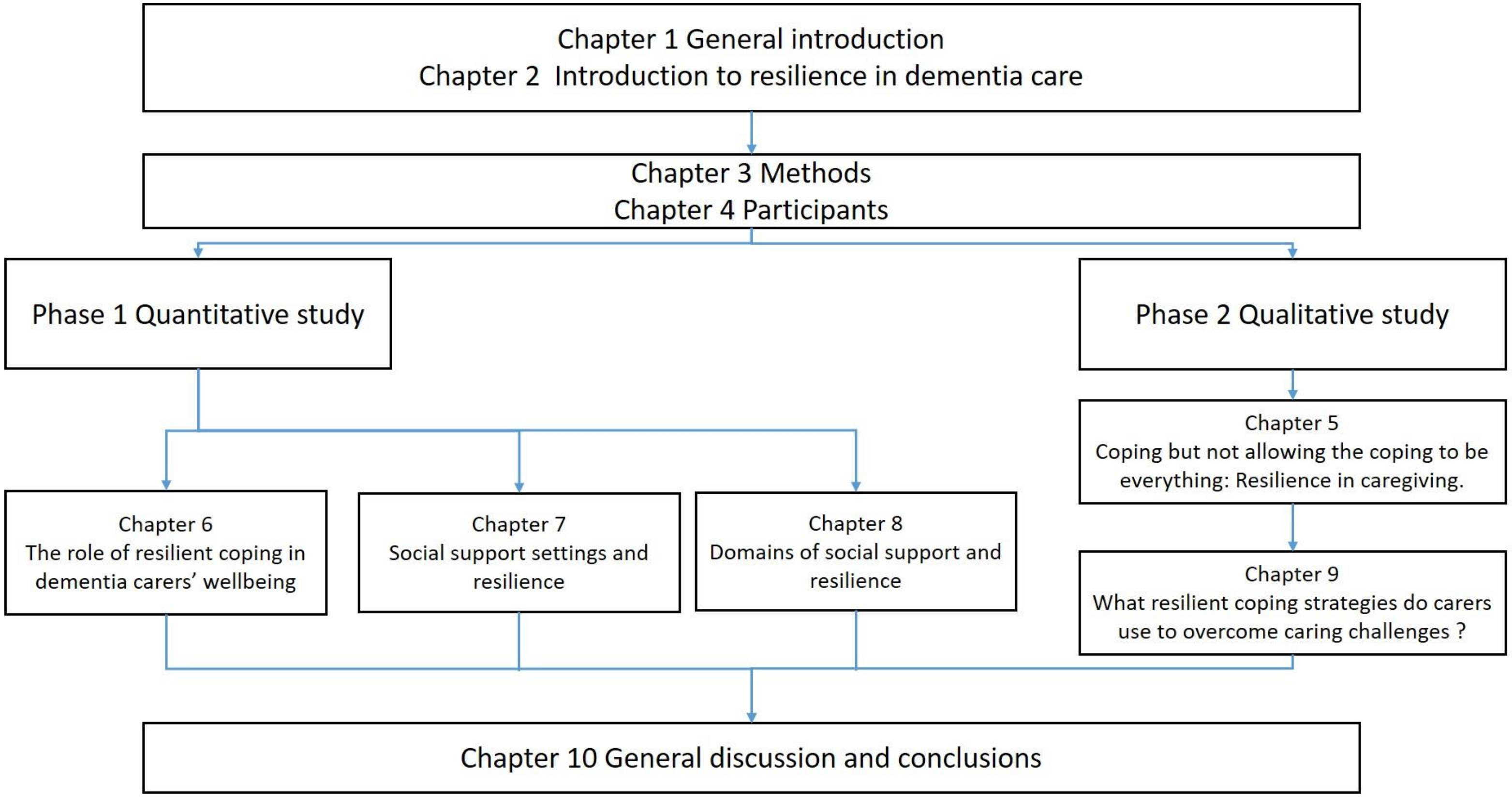


**Figure 1-1** Thesis structure

## 1.3 Glossary of terms

| | |
|---|---|
| **Activities of daily living** | Everyday routines involving functional mobility and personal care, such as bathing, dressing, toileting, and meal preparation**.** |
| **Burden** | The extent to which a carer perceives that their physical, psychological, social, and financial condition has been affected by providing care. |
| **Care** | The provision of help and support for another adult, which may include prompting or assisting with activities of daily living, companionship, or supervision. |
| **Carer** | A person who provides regular unpaid care or support to another individual who cannot care for themselves independently due to illness, disability or age. Carers may be referred to as care partners, caregivers or informal carers. The person may be a relative or friend of the person they care for and may or may not reside with them. |
| **Dementia** | Dementia is a group of symptoms caused by the gradual death of brain cells. The loss of cognitive abilities that occurs with dementia leads to impairments in memory, reasoning, planning, and behaviour. The most common causes of dementia are Alzheimer's disease and vascular dementia. |
| **Dementia Café** | A social support group, open to people with dementia and their carers, which provides informal advice and peer support in a local community setting such as a village hall. An activity programme may be provided, including guest speakers or music sessions. |
| **Distress** | A range of symptoms and experiences of a person's internal life that are commonly held to be troubling or confusing. |

| | |
|---|---|
| **Resilience** | 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 adaption or ‘bouncing back’ in the face of adversity. |
| **Social stigma** | The disapproval of, or discrimination against, a person based on perceivable social characteristics that serve to distinguish them from other members of a society. Social stigmas are commonly related to culture, gender, race, intelligence and health. |
| **Social support** | The perception and actuality that one is cared for and has assistance available from individuals, groups and wider community. |
| **Stress** | The body's response to mental or emotional pressure. |
| **Subjective wellbeing** | A measure of satisfaction with aspects of an individual's life, such as health, control over their life, financial security and being part of a community. |

## 1.4 Motivation for the research

I trained as a Mental Health Nurse in West London in 1995 and went on to complete a Specialist Practitioner degree at Brunel University in 2002. I specialised in dementia care early in my career, working in a variety of community mental health care settings. My current role as an Admiral Nurse focuses on supporting families, including those with a rare dementia, by providing specialist emotional support and advice. I work on an ad hoc basis as a Specialist Advisor for Dementia care for the Care Quality Commission (CQC), supporting unannounced inspections of adult social care providers. I was an active Committee Member for the development of the recently published Supporting Adult Carers NICE Guideline.

During my work as an Admiral Nurse I observed different carer responses to the challenges of supporting a friend or relative with dementia. Some carers were faced with seemingly very complex situations but did not experience the same level of distress as carers who may ostensibly have had less complexity in their caring role. I became interested in understanding the characteristics of carers that may contribute to these differences. This led to the focus on resilience in my thesis.

My PhD was funded through a fellowship from the Research Capacity in Dementia Care Programme, funded by the National Institute of Health Research (NIHR) through the Collaboration for Leadership in Applied Health Research and Care (CLAHRC). I was based at the CLAHRC East of England. The aim of this programme was to support the development of researchers in dementia care, in particular those from clinical backgrounds, e.g. nurses and allied health professionals. The ambition was to support such professionals in undertaking applied research in dementia care and influencing clinical practice.

# 2 RESILIENCE IN CARERS OF PEOPLE WITH DEMENTIA

## 2.1 Foreword

This chapter begins with an overview of the context of providing care for a friend or family member living with dementia. It then uses a narrative approach to provide a critical review of resilience theory and its application to dementia caring. Building on the work of Windle and Bennet (2011), the resilience framework in the context of caring relationships is used to explore individual, community and societal resources that may support carer wellbeing. Finally, this chapter ends by describing the methodological considerations of the study and stating the research questions.

## 2.2 The need for the proposed research

This is an important area of study, as the UK has an ageing population and the number of people living with dementia is expected to continue to increase (Parkin and Baker, 2018). The country has experienced a period of austerity, which has seen the rationalising and restructuring of many health and social care services, including those that support people with dementia (Hutchings et al. 2018). Friends and family members provide an essential resource, for both individuals with dementia and wider society. If all individuals with dementia were fully dependent on formal care provision it would cost an estimated £119 billion (Carers UK and University of Leeds, 2011), therefore safeguarding informal care and family support is central to UK law and policy (HM Government, 2014).

Resilience has been shown to be associated with improved outcomes for the carer and delayed institutionalisation of the person with dementia (Gaugler et al. 2007). A consistent theme throughout the literature (discussed further in Section 2.5) is that personal assets and community resources influence an individual's resilience. However, the ways in which different social contexts and associated demographic factors influence how resilience operates are under-researched (Parkinson et al. 2016). There is a lack of research on the resilient coping strategies that carers employ to support their caring role and whether resilient coping can support carers to use their personal and environmental resources to maintain or promote their wellbeing.

The purpose of this thesis is to help address these gaps in the research, through focusing on resilient coping and using an ecological approach to resilience, as a theoretical framework for this research. The investigation will examine the role of resilient coping in carer wellbeing and the interactions between social support and resilient coping. It will also explore how carers conceptualise resilience and the individual resilient coping strategies they employ while caring for a friend or relative with dementia.

Having a better understanding of the factors associated with resilience in caring could enable service providers to develop interventions to both maintain carers in their caring role and support their health and wellbeing.

## 2.3 Care and support for people with dementia

In the UK there are an estimated 700,000 people looking after a friend or family member with dementia (Alzheimer's Research UK, 2015). It is estimated that one in three people will care for someone with dementia in their lifetime (Department of Health, 2015). The words ‘carer’ and ‘caregiver’ are commonly used in policy, practice, and research to describe a person who supports a friend or relative with an illness or disability over a period of time. Caring can be defined as:

> *‘… the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.’*

(Schulz and Martire, 2004)

There is a significant flaw in this definition – it focuses on the carer as a family member, whereas UK government policy identifies that

> *'Provision of unpaid care' covers looking after, giving help or support to family members, friends, neighbours, or others because of long-term physical or mental ill-health/disability, or problems related to old age.*

(Office for National Statistics, 2011)

Any adult who provides care or intends to provide care to another adult needing support, is entitled to assessment under the provisions of the Care Act 2014 (HM

Government, 2014). The UK census does not currently capture data about the relationship between the person receiving care and support and the person providing it. This highlights the potential challenge in identifying individuals who are not relatives but may require support in their caring role. The Schulz and Matire (2004) definition of caring may be seen as inherently negative in that it emphasises the potential detrimental consequences of caring for the carers' wellbeing. Therefore, it may not be surprising that Alzheimer's International in their 2015 report 'Women and Dementia' (Erol et al. 2015) identify the term 'carer' as a construct bestowed by service providers on friends and relatives, but not always a term that individuals attribute to themselves. Again, this has implications for the identification of carers, as unidentified carers who require support may not be able to access services.

The potential negative consequences of caring for someone with dementia have been explored extensively in the literature. These negative consequences are often conceptualised as a burden. Subjective burden is complex and multi-dimensional, and it is associated with the carer's mental and physical wellbeing (Zarit et al. 1986). Burden is often linked in the literature to psychological distress and mental health. A recent meta-analysis showed that carers of people with dementia have an aggregate prevalence of anxiety (43.6%) and depression (34%); this is higher than both the general population and carers of adults without dementia (Sallim et al. 2015). This has been attributed to a range of factors, including the duration and severity of the care recipient's dementia symptoms (García-Alberca et al. 2011, Kaizik et al. 2017), the type of dementia (Mioshi et al. 2013), and the presence of neuropsychiatric symptoms of dementia or co-morbid disease in the person with dementia (Sado et al. 2018). Carer factors including gender, socio-economic status, low education level and increased number of hours per week spent on caring have also been investigated (Chiao et al. 2015). Carer distress has been associated with abuse of the person with dementia (Cooper et al. 2010).

## 2.4 Psychological and psycho-educational interventions

A range of interventions has been designed to reduce carer depression, anxiety, burden, and stress. Evidence around psychological interventions to address burden and distress in carers is limited by sample sizes, lack of control groups and concerns about the risk of selection bias in the reporting of clinical trials (National Institute of Health and Care Excellence (NICE), 2019). Psychoeducation programmes, cognitive behavioural therapy (CBT) and more recently, acceptance and commitment therapy (ACT), have been used to treat psychological distress in carers. There are conflicting findings in the literature. Multi-component interventions such as the *Strategies for relatives psychoeducation programme* (START) were shown to have a positive effect on carer mood (Livingston et al. 2013). When single approaches (i.e. only one intervention) were used, and CBT was compared to a psychoeducation programme, the CBT group was found to have a significant drop in cortisol levels compared to the psychoeducation group. No differences were found in self-report measures of depression, anxiety, stress, or burden (Aboulafia-Brakha et al. 2014). However, there was a high risk of bias in this study when assessed using the Cochrane Risk of Bias Tool v2 (Higgins et al. 2016). Equally, a randomised control trial, with a lower risk of bias, comparing CBT with ACT and psychoeducation, found that the two therapeutic interventions (ACT and CBT) both improved depression and anxiety symptoms. Benefits were more likely to be sustained in the CBT group (Losada et al. 2015). There are insufficient studies using ACT to fully understand its place in treating psychological disorders in carers (Kishita et al. 2018).

Internet-based psychoeducation courses are showing promising results for improving carer mental health. The *Mastery over dementia* online course employed a range of psychological techniques including problem solving, relaxation, behavioural activation, and cognitive restructuring. It was found to reduce symptoms of anxiety and depression but less than half of the participants completed all eight sessions (Pot et al. 2015).

The Diapason Programme is a 12-session programme targeting carers’ beliefs about dementia and their role, carers’ skills in managing day-to-day challenges, and carers’ social support networks and strategies to access services. There were no significant differences between the intervention and control group in terms of stress, depression, or burden. Only understanding of the disease showed a significant change between groups (Cristancho-Lacroix et al. 2015).

The *UnderstAID* intervention (Núñez-Naveira et al. 2016) has five learning modules that provide information about dementia and signpost carers to other resources. There is the option to add personal details and receive more tailored information e.g. for a stage of dementia or for particular behavioural problems. The intervention improved depressive symptoms, but carers gave low satisfaction scores, especially regarding the section about social support, which carers would have liked to have been written by other carers in a similar situation, rather than by professionals.

There is limited evidence to be able to compare the efficacy of 1:1 face-to-face, group-based, or internet-based interventions. However, qualitative studies have found that carers describe the benefits of group psychoeducation courses. The perceived benefits of group sessions include the carer being able to develop greater understanding and patience with the person with dementia, improved coping skills and developing a social support network (Milne et al. 2014). A single study that evaluated the acceptability of internet-based courses found ‘little acceptance’ and that carers would prefer more social and individualised modes of delivery (Cristancho-Lacroix et al. 2015).

In summary, the prevention and treatment of morbidity in caring is a priority, although the current NICE guidance for dementia does not specify any particular intervention (National Institute for Health and Care Excellence (NICE), 2018b). Interventions that specifically promoted practical coping strategies were acceptable to and perceived as beneficial by carers. Where carers present with mental health problems such as anxiety or depression, both CBT and ACT can be useful to reduce symptoms. There is insufficient evidence to say whether these programmes prevent distress. Online courses and interventions may also bring benefits to mental health, but interventions need to have a higher degree of personalisation to improve their acceptability to carers.

## 2.5 Positive aspects of caring

The positive aspects of caring are not simply the absence of feelings of burden, they include companionship and the sense of caring being rewarding or fulfilling (Cohen et al. 2002). These positive aspects of caring have important benefits for both the carer and the person with dementia. They have been associated with significantly lower depression and burden (Cohen et al. 2002). Carers who report higher levels of satisfaction in their caring role are also less likely to place the person with dementia in a residential or nursing home (Roff et al. 2004).

Factors that promote the positive aspects of caring include a sense of doing a ‘good job’, feeling appreciated, having the opportunity to build a stronger relationship with the person with dementia and reciprocating earlier care received (Peacock, et al. 2010). The existential perspective of finding meaning has been suggested as a positive coping strategy that partially mediates feelings of burden (McLennon et al. 2011). Finding meaning was associated with maintaining a positive attitude and a continuation of a loving relationship; it was sometimes viewed in the context of the carers' faith, which provided both meaning to their role and strength to continue to provide care (Shim et al. 2013). A key variable in experiencing caring as a positive experience was acceptance of the situation (Shim et al. 2012). Although ACT is being used to treat psychological distress, it may also help carers as a measure to promote the positive aspects of caring (Lloyd et al. 2016).

The relationship in the caring dyad is an important factor for the positive aspects of caring; adult child carers identified personal growth as a notable outcome. Caring helped them to gain confidence in their ability to handle difficult situations in the future and to learn about themselves. Spousal carers focused on improvements in their relationship with the person with dementia (Lloyd et al. 2016). This variance in reporting positive aspects of caring may reflect the different ages and life stages at which the individual begins caring; older carers may have already developed a range of strategies to use in response to life's challenges.

## 2.6 Resilience

Many carers identify positive aspects of caring and continue to look after the person with dementia throughout the duration of the illness, despite the increasing challenges that may arise (Cohen et al. 2002). This observation that some carers find caring life enhancing suggests the presence of resilience (Gaugler et al. 2007). Someone who perseveres in the face of adversity or adapts to a new situation without experiencing personal distress is considered resilient (Garity, 1997; Mealer et al. 2014; Rutter, 1987).

The literature around resilience spans over 50 years. It is extensive, disjointed and carries many debates and divergent ideas. Resilience research originally focused on high-risk populations with an emphasis on young people who showed the ability to withstand the psychological, socio-economic, developmental, and environmental stresses they encountered in their early lives (Rutter, 1987). It represented a paradigm shift from focusing on pathology and risk factors that lead to distress and social difficulties, to the identification of strengths and assets within the individual (Richardson, 2002). However, the field of research has expanded to many other areas and resilience is now the subject of many multi-disciplinary projects to address disturbance, distress, and change (Biedermann et al. 2018). The literature gives no definitive operational meaning or model of the term resilience. It is an important debate (Southwick et al. 2014) as the lack of a unified definition has led to criticism of resilience theory (Kolar, 2011; Fletcher and Sarkar, 2013). Instead of one definition, a range of domains is often suggested and interchangeable terms of ‘hardiness’ and ‘robustness’ appear in the literature. These diverse viewpoints have been much discussed and developed over the years; key theorists identify that resilience is either: 1) a pre-existing personality trait; 2) a neurobiological process; 3) an outcome; or 4) a dynamic process of psychological adaptation. These four viewpoints are examined in turn and their application to dementia caring is discussed.

### *1)Resilience as a personality trait*

Resilience as a personal attribute forms the foundation of some of the earliest definitions. Personal resilience was thought to be related to a ‘resilient profile’, a list of attributes observed in individuals, usually children, who had experienced trauma but who had ‘better than expected outcomes’ (Luthar et al. 1993). Resilience was considered a stable personality trait that ‘moderates the effects of stress and promotes adaptation’ (Wagnild and Young, 1993:167). In considering the profile of psychological traits of resilient individuals, Rutter (1987) highlights self-efficacy, self-esteem, and problem-solving skills as characteristics of resilient individuals. Others identify the traits of self-confidence, self-discipline, religiosity, and control over one’s environment as indicative of resilience (Beardslee, 1989; Masten et al. 1999). A conceptual analysis found 14 separate definitions of resilience (Gillespie et al. 2007) but concluded that self-efficacy, hope, and coping were the defining characteristics of resilience. These personality traits help individuals to accept their current situation and adapt their response to stressful events, acting as a protective factor against distress (Windle et al. 2010).

People with greater resilience are better able to utilise their personal assets and they have access to resources within their social and physical environments (Bennett and Windle, 2015). The role of resources such as health and social care services are further discussed below, within section 2.6. Resilience can also be defined in terms of a person’s motivation to use these personal and social resources and achieve personal growth through acquiring wisdom and self-actualisation (Richardson, 2002). This is an interesting theory for resilience in care, as motivation to start or continue to provide care can also have implications for carer wellbeing

(Quinn et al. 2009), with carers whose motivation is derived from feelings of guilt or duty being more likely to experience distress (Pyke and Bengtson, 1996).

### *2) Resilience and neurobiology*

Developing the earlier work on the resilient personality, attention has now shifted to other predisposing factors. The biological profile of resilience (Charney, 2004) identifies the role played by neurochemicals, neuropeptides, and hormones in mediating an individual’s psychological response to distress. Neural mechanisms of reward, fear and social behaviour were found to be related to the personal characteristics of resilient individuals (Feder et al. 2009). Charney (2004) argued that some people were biologically resistant to the negative effects of stress. Current research is exploring the potential to identify the neurophysiological substrates that determine a predisposition to resilience to stress and depression (Han and Nestler, 2017). In the future, this may generate possible interventions to induce this resistance in vulnerable populations (Faye et al. 2018).

### *3) Resilience as an outcome*

Resilience as an outcome has been defined primarily in terms of the absence of psychological distress, in an individual who has survived a traumatic event (Bonanno et al. 2006). Markers such as physical, social, and intellectual development have been used to identify individuals with ‘exceptional outcomes’ in the earliest wave of resilience research (Werner et al. 1967). Prospective longitudinal research studies have focused primarily on children and young people who have faced significant trauma (Masten, 2014a). Resilience as an outcome for carers is an under-researched area, lacking the longitudinal studies conducted in other populations. As dementia is a neurodegenerative condition from which the individual will not recover, the disease is likely to provide constantly changing challenges and experiences for the carer. Therefore, the process of developing resilience in this context is not straightforwardly sequential or linear. It may be determined by the factors related to the individual prior to their caring role and the context within which they now find themselves.  Longitudinal studies measuring resilience to distress, examining neuro-biological variables, socio-environmental factors before and after periods of adversity, and pre- and post-intervention have been identified as an important next step in resilience research (Southwick et al. 2014).

### *4) Resilience as a process*

The conceptualisation of resilience as a process is more applicable to the current research. Process definitions endeavour to describe the positive adaptations that people exhibit, despite experiences of adverse events or trauma (Luthar et al. 2000). Windle (2011) argues that this is what distinguishes resilience from hardiness, the latter being a stable personality trait, as opposed to resilience, which is dynamic and subject to change over the individual’s lifetime. The exposure to adversities such as poverty or abuse are described as a precursor to resilience. Luthar et al (2000) define positive adjustment to adverse life events in terms of social competence and functioning. They acknowledge that the absence of behavioural or emotional maladjustment may be an equally valid measure of resilience and suggest that resilience should be measured by the most appropriate outcome for the adverse event and population being studied, for example, measuring long-term educational and employment outcomes in children who faced trauma in early life. Rutter (2012) asserts that resilience is wider than the individual context and incorporates factors extrinsic to the individual, including their family and social influences. Social support, relationships with family and peers, and secure attachment styles are positively correlated with resilience (Corcoran and McNulty, 2018).

Limitations in personality and neurobiological theories where an individual is either resilient or not have been acknowledged (Oshio et al. 2018; Kalisch et al. 2015), as resilience is understood to be influenced by external factors (Bennett and Windle, 2015; Ungar, 2011). It is also argued that all individuals have the capacity to be resilient, regardless of their pre-existing personality or genetic factors. Resilience has been referred to as ‘ordinary magic’ (Masten, 2001). This suggests that resilience is universal, and differences arise due to an individual’s personal and environmental resources. Personality, outcome and process descriptions may have greater or lesser relevance in a particular context; it is important to note that resilience research requires an appreciation of the interconnectedness between both outcome and process (Van Breda, 2018). Conceptualisations of resilience within the specific context of dementia caring are further investigated in Chapter 5.

## 2.7 An ecological approach to resilience: The resilience framework in caring relationships

The ecological approach to resilience in caring brings together the intrinsic resources of personality, neurobiology and health with extrinsic factors such as social support and formal care providers. The resilience framework (Figure 2-1) (Windle and Bennett, 2011a) provides a theoretical framework of resilience in caring relationships. It shows the interaction of resources at three levels, which were derived from the Ecological Systems Theory (Bronfenbrenner, 1977). Originally, this theory focused on childhood and it identified ‘layers of environment’, which impact on the individual’s development. It has now been applied to other populations and is used here to identify a number of assets and resources that may pose a risk to, or act to promote, carer resilience at individual, community and societal levels. The framework identifies that the discrete resources within each level interact with each other, and no single level has greater or lesser influence on the consequences. Carers may have greater or lesser access to these resources, which may bring either risks (for example to wellbeing) or resilience. The framework is context specific and indicates that outcomes, described here as consequences, may include further caring challenges and wellbeing or institutionalisation.

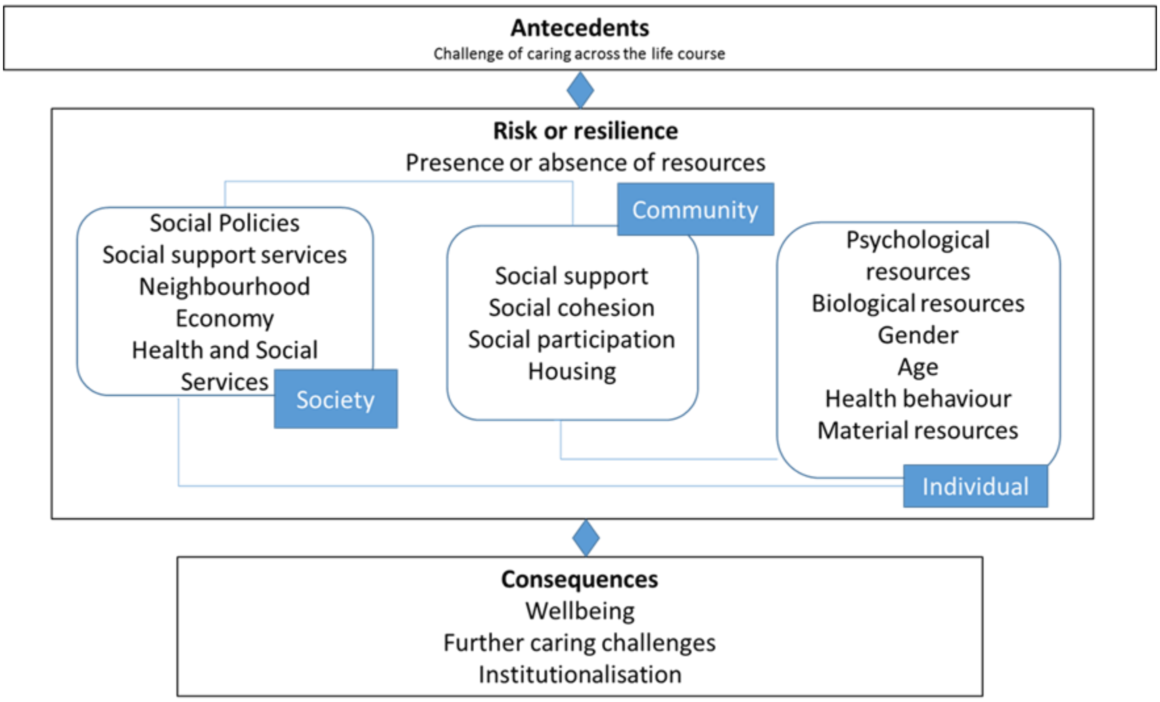


**Figure 2-1** The resilience framework in the context of caring relationships (Windle and Bennett, 2011)

The framework suggests that an ‘antecedent’ adversity is required to trigger the interplay of risks and resilience. In this case, the antecedent is ‘challenge of caring across the life course’. The figure shows the relationships between caring challenges and the presence (or absence) of resources at the individual, community, and societal levels and the potential consequences. Resources identified include a range of individual and inter-related influences on wellbeing, including genetic, environmental, and social processes (Masten and Narayan, 2012), which are thought to contribute to improved psychological outcomes.

### *Antecedents: changing roles and relationships*

Resilience starts with the assumption that given the same pattern of adversity or stress there will be a marked heterogeneity in the response within the population (Rutter 2012). Adversity in resilience research can be either acute, such as a natural disaster, or chronic (Bonanno and Diminich, 2013). Caring for a relative with dementia may extend over a period of many years with fluctuating levels of challenge, and so is considered a chronic adversity.

For some people there is a period of transition from being the person’s husband, wife, child or friend to also becoming identified as their carer. Equally, an individual may care for more than one person and experience different challenges within each caring role. Carers who are not family members have the same rights in law in terms of assessment and support as family carers. The resilience framework identifies that there may be different caring episodes across the life course, but it does not distinguish how resources or risks may change with each caring role.

### *Consequences*

The framework identifies three potential consequences: further caring challenges, wellbeing, and institutionalisation. Wellbeing here may be considered as maintenance or recovery of the carer’s health and wellbeing but should also include positive aspects of caring as discussed earlier in section 2.4. Resilient carers were those who not only ‘stayed positive’ but used caring for their relative as an opportunity to gain extensive knowledge and skills (Donnellan et al. 2015). Consequences identified in the framework need not be mutually exclusive; carers may face further challenges but regain a sense of wellbeing (Gaugler et al. 2000). Equally, caring challenges may not end when the person with dementia moves into a care setting (Alonso et al. 2017).

### *Risks or resilience: Individual resources*

Resilience has been suggested to be the intervening factor between the risk factors associated with caring and the utilisation of personal resources (Bennett and Windle, 2015; Windle, 2011; Windle and Bennett, 2011a; Mohaupt, 2009). The resilience framework identifies gender, age, psychological resources, health behaviour and material resources as individual-level factors These individual risk and resilience factors have been discussed in section 2.5; the psychological factors identified within the framework reflect those used to describe resilience as a personality trait, i.e. self-efficacy (Bandura, 1982), optimism, hope, faith and intelligence (Masten, 2015). There are inconsistencies in the literature regarding the factors identified within the individual domain of the resilience framework. Kinship to the person with dementia has been identified as both a risk and a resilience factor. Spousal relationship is associated with increased burden and psychological distress (Bruvik et al. 2013) and improved mental health and lower burden when spouses were compared to other family carers (Conde-Sala et al. 2010). However, no relationship was found between overall carer resilience and marital relationship (Fitzpatrick and Vacha-Haase, 2010). There is little research examining gender and resilience (Liu et al. 2015). Being male has been associated with higher resilient coping in the general population (Kocalevent et al. 2017); however, another study taking a wider view of resilience found no differences in scores between gender or ethnic groups (Karaırmak and Figley, 2017). Resilience and factors related to the context of care have been examined and it has been noted that co-residence with the person with dementia has been associated with lower carer resilience (Gaugler et al. 2007), and higher resilience is associated with lower burden (Dias et al. 2015; Senturk et al. 2018). There may be inconsistencies in these studies as various instruments were used to measure resilience and different definitions of resilience were applied.

### *Risks or resilience: Community*

Resilience, specifically resilient coping, is positively related to improved carer outcomes and is associated with the greater availability of social support (Ruiz-Robledillo et al. 2014) and lower levels of burden, stress and depression (O'Rourke et al. 2010). Resources within the community level include support from friends, family and neighbours and the opportunity for social participation. The resilience framework emphasises social support and participation as key resources for carer wellbeing. Interactions with others in a similar situation through social support settings such as carers groups are useful and can support carer wellbeing (National Institute for Health and Care Excellence (NICE), 2018b). Stable and supportive friendships were found less frequently in non-resilient carers but this deficit may be ameliorated by attendance at a dementia support group (Donnellan et al. 2016).

In the UK, the National Institute for Clinical and Health Care Excellence (NICE), which advises on effective health and social care interventions, recommends the provision of supportive psychosocial interventions for the person with dementia and their carer that they can attend together, to reduce stigma and improve wellbeing (National Institute for Health and Care Excellence (NICE), 2018b, Department of Health, 2009). As a response to this need, Dementia, Memory or Alzheimer’s Cafés are promoted as an approach to improve wellbeing and social support. The concept originated in the Netherlands (Jones and Miesen, 2011), where families living with dementia receive a psycho-educational programme facilitated by health care professionals that covers types of memory problems and communication and provides sources of help and information. Dementia Cafés offer a mutually supportive setting for both the person with dementia and their carer; this supportive environment has been found to promote the relationship between the person cared for and the carer. Connections with peers are also made (McFadden and Koll, 2014). Cafés are now operating in 15 countries worldwide (Alzheimer's Disease International, 2017) and are varied in their care provision; there is no single model used internationally. In the UK, Dementia Cafés run in a variety of formats. Activities vary but are designed to promote the cognitive and social wellbeing of attendees. There is often entertainment, or a guest speaker, lunch or afternoon tea may be served and there may be reminiscence activities, quizzes, and music, singing or arts and crafts sessions. National charities such as AGE UK, the Alzheimer’s Society or local voluntary groups host the majority of UK cafés. The continued development and expansion of the model supports the suggestion that cafés offer economically viable post-diagnostic support for people with dementia and their carers (Alzheimer's Disease International, 2017).

Studies have defined support in different ways: network size, frequency of contact, type of support and satisfaction with support have all been measured. The satisfaction with the social support offered and the carer’s perceptions of the support are more significant for maintaining resilience than the network size or frequency of contact (Dias et al. 2015). Carers with high resilient coping are more likely to be goal-directed, have a belief that they can overcome challenges and experience greater subjective wellbeing (Sinclair and Wallston, 2004; Tomás et al. 2012). However, little is known about whether carers with high resilient coping can also overcome the potential difficulties of maintaining a social support network in the context of providing care for a friend or relative with dementia. This suggests that understanding the mechanisms of social support in dementia care is important for targeting resources and supporting friend and family carers to access social support settings such as Dementia Cafés, which may support resilience.

### *Risks and resources: Societal*

Societal resources in the resilience framework include social policy, health and social care services, and neighbourhood factors. These societal factors have been less well studied than the individual-level factors. Community resilience is a priority in UK government policy, with businesses and individuals being encouraged to work together to ‘prepare respond and recover from disruptive challenges’. The primary focus is resilience to ‘emergencies and disasters’, e.g. the maintenance of essential services following a terrorist attack. The need to identify and support vulnerable individuals in the community is a priority for long-term community resilience (Cabinet Office, 2016). Higher individual resilience has societal benefits. Higher resilience in family carers has been associated with a lower risk of domestic abuse of the person with dementia (Serra et al. 2018) and lower levels of institutionalisation of the person with dementia (Gaugler et al. 2007). This therefore reduces the wider societal financial burden of dementia care provision.

Engaging with formal health and social care providers is positively associated with resilience in carers. The use of respite care, day care and domiciliary care services predicted higher carer resilience (Gaugler et al. 2007). However, some carers chose not to use services or found that services did not meet their specific needs. Inconsistent, insufficient provision, poor-quality care and difficulties navigating the system were all reasons given for not engaging with services (Peel and Harding, 2014). This suggests that there are significant barriers to carers accessing and using services: the use of formal health and social care services can only promote resilience when needs, expectations and delivery are aligned.

Dementia Friendly Communities have been suggested as a key societal intervention to support families living with dementia and to build resilience (Local Government Association, 2015). As of March 2017, there were 196 communities across England and Wales with recognised ‘Dementia Friendly’ status (Woodward et al. 2018). A

Dementia Friendly Community can be a street, village, town or city, and is defined as a place where:

> *'People with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them'.* (Green and Lakey, 2013).

Although the evaluation of the impact of Dementia Friendly Communities is ongoing, initial research has identified that they can raise awareness of the needs of people with dementia and their carers in the wider community. When viewed within the resilience framework, a Dementia Friendly Community has the potential to provide resources for resilience.

*Criticisms of the resilience framework*

One criticism of the framework is that while it assists with the identification of resources at each level, it does not differentiate between those that bring risk (for example to the carer's mental health) or those that promote resilience. Equally, it cannot differentiate where one factor may have different consequences, dependent on its context. Each resource may act as a protective or risk factor. For example, the presence of effective and supportive social interactions with friends and family has been associated with carer wellbeing, but equally negative interactions can detract from wellbeing (Wittenberg-Lyles et al. 2014). The resilience framework does not capture this dichotomy in factors. Therefore, the conclusions that can be drawn about whether the presence or absence of the factors identified in the framework contribute to risk or resilience for the carer are limited. A further concern of the ecological approach is who should define the risk and resilience factors (Hutcheon and Lashewicz, 2014). The factors described in the framework have been identified based on the current literature, but it may be that specific cultural contexts or individual carers have varying ideas of what constitutes a risk or a positive outcome. Additionally, the framework identifies the necessity of an antecedent event, but recent evidence has found no correlation between negative life events and resilience, and no change in resilience despite an increase in negative events over time (Karaırmak and Figley, 2017). Resilience studies have consistently highlighted the significance of relationships in the resilience process and greater emphasis is now placed on the social environment of the individual rather than their personal psychological resources (Van Breda, 2018). However, there is a gap in our understanding of how the framework is operationalised in the context of dementia care provided by friends and family members and the specific factors at each level (individual, community or societal) that promote resilience.

## 2.8 Measuring resilience

Different approaches have been taken to quantify and estimate resilience in individuals. Resilience is considered multi-faceted, therefore one approach to quantifying it is by measuring its constituent parts. Studies have used multiple questionnaires to measure self-efficacy, physical health, depression, hopelessness, anxiety, optimism, carer burden, coping strategies and social support, and these have then been drawn together in analysis to identify resilience (O'Dwyer et al. 2016; Kim and Knight, 2017). Other studies have aimed to measure resilience as a single phenomenon (Loprinzi et al. 2011; Wilks et al. 2018). This has been hampered by the lack of a clear definition and the wide interpretation of the term. There is a range of resilience scales that focuses on differing attributes and contexts. Many of these have been developed to study a specific population group in a particular context, e.g. the Resilience Factors Scale was developed to investigate resilience in Thai adolescents in the context of alcohol use (Takviriyanun, 2008). Others were developed with no clinical applications suggested, e.g. the Brief Resilience Scale (Smith et al. 2008). The Connor-Davidson Resilience Scale (CD-RISC) (Connor and Davidson, 2003) is a widely used scale and it has been used within clinical trials with people with post-traumatic stress disorder and with subjects from primary care and mental health care outpatients. However, a methodological review of scales found no gold standard, a lack of validation and unclear conceptual or theoretical frameworks underpinning the measures (Windle et al. 2011).

There is no definitive scale to measure resilience and none of the available scales have been validated in carers. The Brief Resilient Coping Scale (BRCS)(Sinclair and Wallston, 2004) is used throughout this thesis and measures resilience as a unidimensional construct. This scale gives an overall score derived from the sum of the scores of four resilient coping strategies. It acknowledges that individuals have the capacity to have varying resilient responses to stressors. This scale was chosen as it has demonstrated adequate levels of reliability and validity (Sinclair & Wallston, 2004) and normative data have been generated for different age groups for both men and women (Kocalevent et al 2017). This facilitates comparisons with other populations and clinical groups.

In light of the heterogeneity of the resilience definitions, theories and measures highlighted, this thesis identifies a specific aspect of resilience to focus on, namely ‘resilient coping’. Resilience and coping are closely connected concepts. Coping refers to the

> *‘constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands’* *(Lazarus and Folkman, 1984)*

It is essentially an individual feature and one that implies some direct action, a personality trait, and a way of responding to stress (Hamill, 2003). Resilience differs in that it also requires a supportive social context, which influences the individual’s ability to cope (Rutter, 2012).

Resilient coping draws together the personal characteristics and behaviours of resilience into a practical response to the challenges brought about by caring for a relative with dementia. It refers to the beliefs and activities that allow an individual to overcome difficulties arising in their social ecology (Mukherjee and Kumar, 2017). Individuals with a resilient coping style acknowledge that struggles and challenges can give rise to personal growth (Sinclair and Wallston, 2004; Ungar, 2011). Resilience requires the individual to have better than expected outcomes (Werner, 1992) i.e. thriving not simply surviving.

## 2.9 Summary

Resilience is considered to be multi-dimensional, and dependant on an individual’s personal resources and their social ecology. It does not protect an individual from adverse life events but may enable them to move forward with fewer negative consequences such as long-term psychological distress.

The lack of an acknowledged definition of resilience as a concept is recognised, but some theorists argue there is no need to aspire to a single definition of resilience (Southwick et al. 2014) and that it is acceptable to have contextual definitions. However, that context must be clearly stated (Wright and Masten cited in Southwick 2014). There is value in looking broadly at the literature and it can be suggested that resilience begins with the interplay of personal attributes such as hope and self-efficacy but requires the process of adaptation within a supportive social context to achieve a positive outcome. In this thesis, caring for someone with dementia is the context that gives rise to predictable threats to resilience due to the physical, social, psychological, and financial demands placed on the carer.

As such, this thesis uses the following definition of resilience:

> *Resilience is 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 adaption or 'bouncing back' in the face of adversity'.* Windle 2011

Directing attention away from carer burden models towards resilience and resilience building effectively reframes how health and social care practitioners and carers themselves perceive caring, with the focus on the positive experiences of successful care (Parkinson et al. 2016).

Exploring the interactional processes between the individual (psychosocial and demographic characteristics), significant others (social support network) and systems (health and social care services) and examining their relationships with resilient coping and wellbeing, will aid understanding of effective strategies to support carers of people with dementia.

## 2.10 Overview of research aims and questions

This thesis aims to operationalise the resilience framework in caring relationships (Windle and Bennett, 2011) by exploring the resources identified at each level of the framework, contributing to the current literature on what constitutes resilient coping in friends and family carers supporting a person with dementia. There are two key objectives within this aim.

Objective 1. To investigate the role of resilient coping in relation to health and wellbeing outcomes for carers. It is hoped that by identifying any specific benefits associated with resilience it will be possible to better identify and target resources to support people in their caring role.

Objective 2. To draw on the quantitative study findings and the scientific literature to further explore resilient coping strategies used by carers. Successful identification of effective strategies used by highly resilient carers may assist health and social care practitioners to support the development and use of these strategies in less resilient carers.

The following seven research questions derive from the above objectives. Figure 2-2 shows how the thesis chapters map to the resilience framework.

Individual level of the resilience framework

RQ1 How do carers conceptualise resilience? (Chapter 5).

RQ2 What socio-demographic factors influence resilient coping in friends and family members who provide care? (Chapter 6).

RQ3 Can resilient coping act as a mediator in the carer-wellbeing relationship? (Chapter 6).

Community level of the resilience framework

RQ4 What factors predict carer attendance at social support settings? (Chapter 7).

RQ5 What role do different types of social support play in carer resilience? (Chapter 8).

Society level of the resilience framework

RQ6 How does carers' perceived level of resilience compare with the level of resilience when measured on a standardised tool? (Chapter 5).

RQ7 What resilient coping strategies do carers use to overcome caring challenges? (Chapter 9).

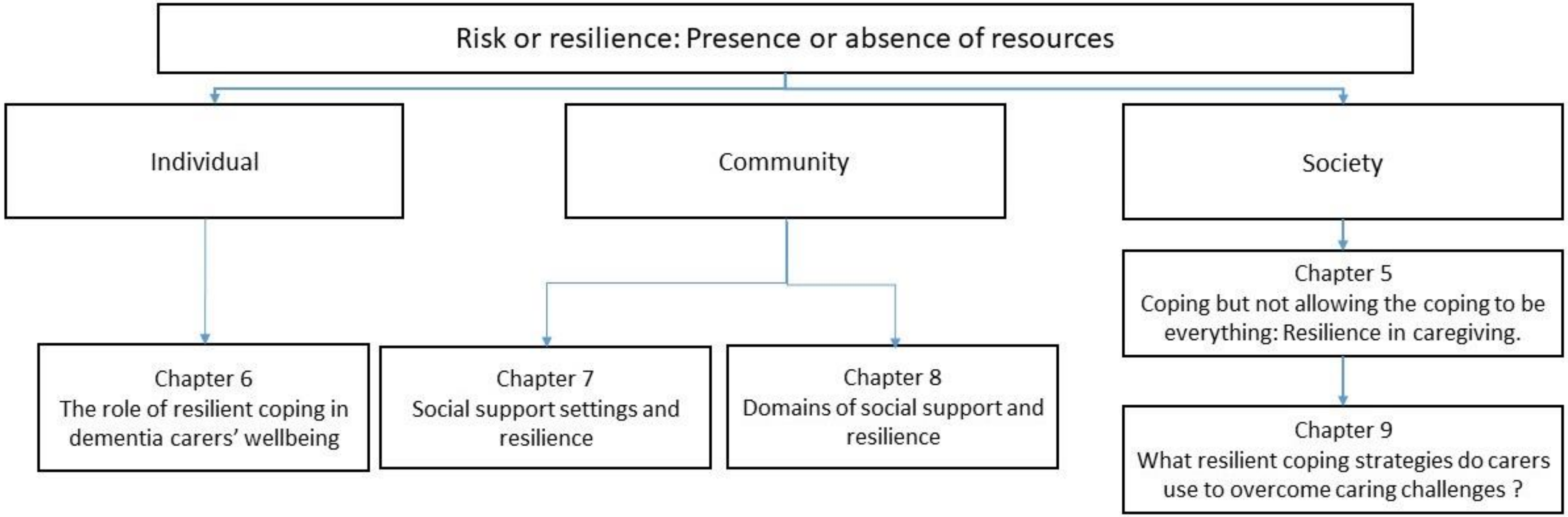


**Figure 2-2** Thesis chapters mapped to resilience framework

# 3 METHODS

## 3.1 Foreword

To answer the research questions outlined in the previous chapter, this thesis used a two-phase sequential mixed-methods design (see Figure 3-1). In phase one, data were collected via a cross-sectional survey and used to answer the following research questions:

RQ3 Can resilient coping act as a mediator in the carer-wellbeing relationship? (Chapter 6).

RQ2 What socio-demographic factors effect resilient coping in friends and family members who provide care? (Chapter 6).

RQ4 What factors predict carer attendance at social support settings? (Chapter 7).

RQ5 What role do different types of social support play in carer resilience? (Chapter 8).

In phase two, semi-structured interviews were conducted with a subset of survey respondents. These qualitative data were analysed in two distinct phases. The first is presented in Chapter 5 and answers the following two research questions.

RQ1 How do carers conceptualise resilience? (Chapter 5).

RQ6 How does carers' perceived level of resilience compare with the level of resilience when measured on a standardised tool? (Chapter 5).

A second analysis of the interview data was conducted to answer the final question.

RQ7 What resilient coping strategies do carers use to overcome caring challenges? (Chapter 9).

This chapter details the ethical considerations, stakeholder involvement, data collection methods, questionnaires and analytic strategies used. It concludes with a summary of how the findings from across the two phases were integrated and synthesised.

## 3.2 Rationale for mixed-methods approach

The overarching aim of the thesis is to explore resilience in carers supporting a person with dementia. A mixed-methods explanatory sequential design (Creswell and Clark, 2017) was used. Mixed-methods research uses quantitative and qualitative approaches to capture multiple perspectives and develop new knowledge (Holloway and Galvin, 2016). Data synthesis brings together compatible, relevant data sources to add depth and promote understanding of the topic under investigation. A mixed-methods approach was chosen in this instance for the following reasons:

1) Construct inequivalence occurs often in resilience research as there is a lack of clarity of the concept and it holds different meanings for different individuals and communities (Ungar, 2008).
2) The existing literature uses a range of approaches and proxy measures to quantify resilience.

A strength of the mixed-methods design was that it allowed both of these issues to be addressed. The quantitative approach (cross-sectional survey) focused on a specific construct, i.e. resilient coping, and its relationship with other factors. However, this approach to data collection and analysis could not adequately capture the carers' conceptualisation of resilience and their experience of developing or deploying resilient coping strategies when looking after someone with dementia.

Different approaches are used to answer different research questions within the thesis. As described earlier, the literature review highlighted that resilience can be demonstrated in a multitude of ways across varied contexts. Therefore, it is important to clearly define the concepts under study for both the quantitative and qualitative phases of the research. Resilience research is highly contextual and dependent on understanding both the 'adversity' or antecedent event and the 'consequence' (Masten, in Southwick et al. 2014). Therefore, within this thesis, the antecedent, consequence and construct are clearly identified. Providing care to a friend or relative is the antecedent event. Subjective wellbeing is the measure of adaptive functioning, i.e. the consequence, and resilient coping the construct under investigation. Measuring resilience and wellbeing in this way provides a quantitative, variable focused approach (Howard and Hoffman, 2018) that seeks to explain the relationships between these factors. This approach has previously been used to examine resilience as a protective factor of carer distress (O'Rourke et al. 2010) and the timing of admission of the person with dementia to a care home (Gaugler et al. 2007). This variable focused approach limits the opportunity to identify groups within the population who may differ in their experiences and responses (Howard and Hoffman, 2018). Therefore, to assess the contextual factors that influence how different populations conceptualise resilience, qualitative methods are used to understand what resilience means specifically for carers of people with dementia. The value of understanding the perspectives of specific groups is highlighted by Ungar (2008), who advocates a mixed-methods approach to both measure and understand resilience in specific settings. Consequently, a pragmatic mixed-methods approach is the most appropriate for this research. Figure 3.1 outlines how the quantitative and qualitative approaches come together to give the overall findings.

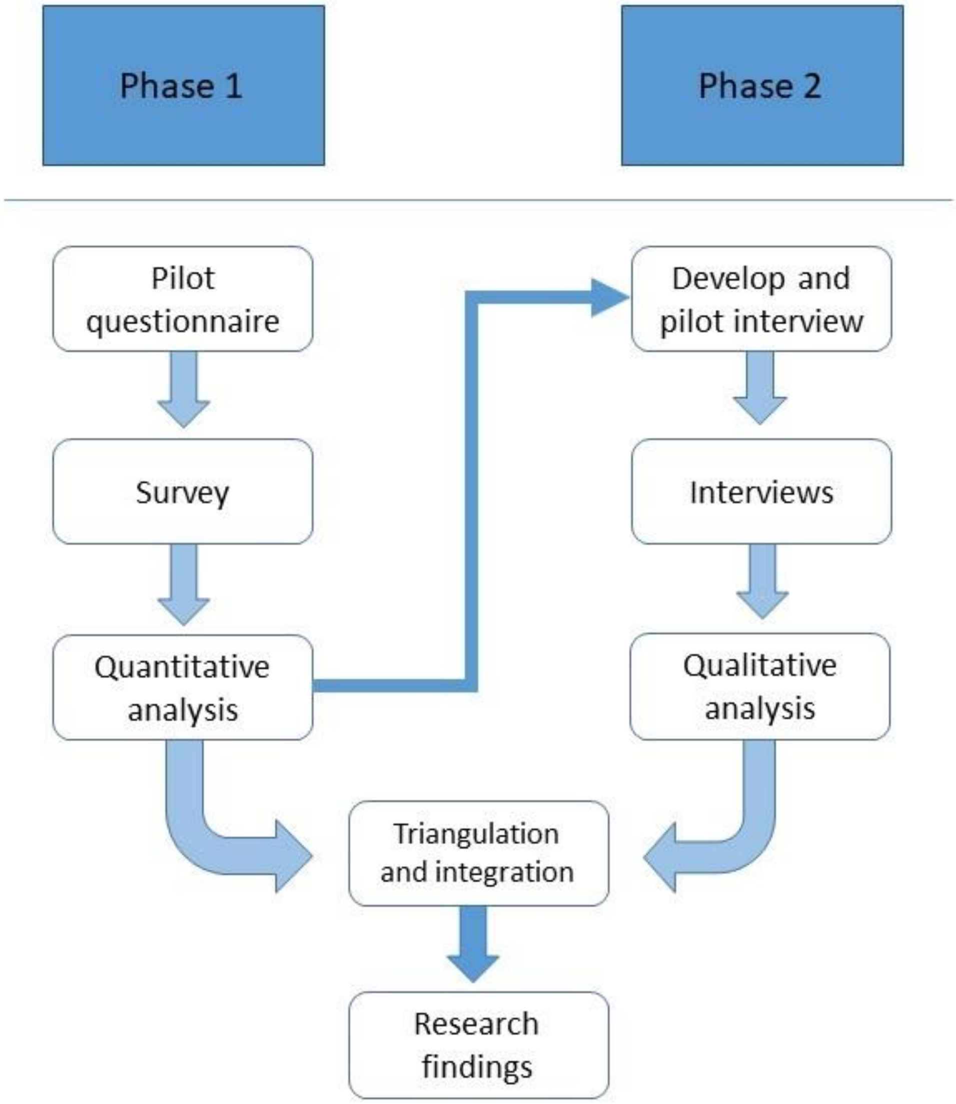


**Figure 3-1** Flow chart describing the two-phase mixed-methods design and triangulation protocol, showing how quantitative and qualitative data were integrated

## 3.3 Ethics

Ethical approval was granted by the Faculty of Medicine and Health Sciences University of East Anglia Ethics Committee – University of East Anglia. Both phases 1 and 2 (cross-sectional survey and qualitative interviews) were approved by this committee (Appendices 12.2 and 12.8). As a member of the Royal College of Nursing I adhered to the ethical guidelines of my professional body (Royal College of Nursing (RCN), 2011) and Good Clinical Practice (GCP) principles derived from the Declaration of Helsinki (World Medical Organisation, 1996).

*Informed consent*

The purpose and nature of the research were explained to the participants and individuals were offered the opportunity to clarify the information they were given. All participants completed an informed consent form for each phase of the study (Appendices 12.3 (phase one) and 12.9 (phase two)). The forms detail how the participant may withdraw after informed consent has been given and at any time during the research. No participants withdrew their consent.

*Adverse events*

The potential for distress to the carer was considered, given that some people could find completing a survey about their experiences of supporting someone living with dementia upsetting. Information about relevant support agencies and telephone helplines were therefore included at the end of the survey.

The potential burden on participants was considered carefully. For this reason, abbreviated rating scales were used where possible, e.g. the DASS-21 was used in favour of the full version. This reduced the time that the participants spent completing the survey but retained the validity of the data.

A system was put in place that enabled the participants to raise comments or complaints with me in the first instance and then with my PhD Supervisor. A member of the University of East Anglia faculty who was independent of the research project was also available to be contacted should a participant wish to raise a further concern or complaint. Contact details for all these sources were provided on the participant information sheets (Appendices 12.4 and 12.10).

Procedures were put in place for the eventuality that risks to the wellbeing of the carer or person with dementia were noted (e.g. safeguarding). No such risks or events arose.

### *Debriefing*

As the interviews in phase two had the potential to cover sensitive or emotive issues, the potential for distress was perhaps greater than in phase one. At the end of the interview I spent time with each participant to answer further questions or raise any concerns I had noted that were beyond the scope of the research but potentially relevant to safeguarding the carer or person with dementia. One participant raised concerns about her mental health and I used the debriefing session to ensure she had appropriate support in place and knew who to contact should she require additional support for herself or the person she cared for.

Where carers chose face-to-face support to complete the survey or arranged interviews at their home address, I was mindful of the potential for distress to the person with dementia. Where possible I arranged these visits for times when the person with dementia was elsewhere. If that was not possible, I conducted the interview in a separate room in their home.

### *Data management*

Each participant’s inclusion in the study was confidential and each participant was assigned a study number (phase one analyses) or a pseudonym (phase two analyses) in order to maintain anonymity.

The safeguarding of participant data was extremely important, and steps were taken to ensure that all data were anonymised prior to use. Standard good clinical research practices were followed to ensure the confidentiality of electronic and hard-copy data, in keeping with the General Data Protection Regulation 2018 (General Data Protection Regulation (GDPR), 2018). Study data were only available to members of the research team for permitted research and administrative activities.

All data were stored under secure conditions within a research office on the University of East Anglia site. Hard-copy data were stored in a locked cabinet in a locked room to which only research staff had access; electronic data were stored on secure servers and managed using databases encrypted with industry standard cryptographic methods. They were also protected by passwords. Data will be held for a minimum of 10 years.

### *Researcher safety*

Researcher safety was also very important. A lone working system was in place, using the ‘Guardian24’ app. Guardian24 is an accredited lone worker safety service that can be used via a mobile phone. This service enabled other members of my team to see that I was safe when returning from visits or travelling between settings.

*Researcher training*

I renewed and updated my GCP training with the NIHR in March 2016 (month 6 in my PhD programme). This was a full-day interactive taught session and workshop with researchers from across the health care sector, including general, mental health, paramedic, and community care settings. I had the opportunity to explore and develop an understanding of the international ethical, practical, and scientific standards for clinical research through discussion, workshop activities and sharing of good practice. I also attended the University Postgraduate Researcher training on ethics in research and other relevant professional development sessions; details are given in Appendix 12.1.

## 3.4 **Patient and public involvement**

*Involvement in highlighting relevant research areas*

Prior to the design of the research, in my role as an Admiral Nurse I visited Dementia Cafés and carer groups and approached carers and people living with dementia to discuss their research interests. A key theme raised by carers included keeping themselves mentally and physically well and being able to continue to care. This led to an interest in resilience as a potential defining characteristic between carers who thrive in their caring role and those who do not.

Further patient and public involvement was also sought in piloting the survey and giving feedback on the design and layout of the questionairres and the development of the interview schedule. For instance, people gave feedback on the length of time taken to complete the survey and the language used within publicity materials. Further details of this involvement are given in section 3.7.

*Dissemination of findings*

The findings of the PhD were presented at a range of stakeholder events. These included public events such as the Dementia Open Forum held at the University of East Anglia. People with dementia, their carers and local health and social care providers are active participants in the forum alongside academics and students.

## 3.5 Participants

All participants were carers of people with dementia. In this thesis, the term ‘carer’ is used to describe an adult who provides unpaid care or support to a friend or family member with dementia (see also glossary in section 1.3). There were no restrictions on the type of care provided or type of dementia of the person receiving care. Further details of the participants are given in Chapter 4.

| Inclusion criteria | Exclusion criteria |
|---|---|
| Adult providing unpaid care or support to a friend or family member with dementia | Providing care on a formal/paid basis or providing care to a person without dementia. |
| Able to complete a survey in English (with support if required) | Unable to understand English<br>Aged under 18 years |

**Table 3-1** Participant inclusion and exclusion criteria

## 3.6 Phase one: Quantitative studies

*Sample size and power calculations*

A priori power calculations were made using G-Power software (v3.1) (Faul et al. 2009), which identified that in order to achieve a power of 0.80 and a medium effect size, a total sample size of 122 was required for phase one. This sample size was not met and the actual power achieved was 0.68 (Chapter 6). The reasons why this sample size was not met are further explored in section 10.5.

*Recruitment*

The participants were recruited in collaboration with Healthwatch Norfolk and the Alzheimer’s Society. Healthwatch Norfolk is a ‘consumer champion for health service users’. It hosts stakeholder events and collates service user feedback about health and social care services, to provide advice and information to service commissioners, providers, and users. Healthcare professionals refer people who have a new diagnosis of dementia to Alzheimer’s Society advisors and support workers who provide information about dementia and local support services. Staff from both Healthwatch and the Alzheimer's Society supported recruitment through sharing the publicity materials for the study at their events and via their mailing lists.

Three approaches to recruitment were used:

1. Face-to-face invitation: myself and members of Healthwatch Norfolk staff presented and explained the project to individuals at Dementia Cafés, support groups and other information events that took place in community settings such as libraries and Town Halls. The approach varied between settings and was determined by the setting co-ordinator's preference – either discussed individually with potential participants or presented to the carers as part of a group support session. Information sheets were distributed at these initial sessions. Second visits were made to the groups' following meetings and survey packs and consent forms were distributed to interested, eligible carers as shown in Figure 3-2.

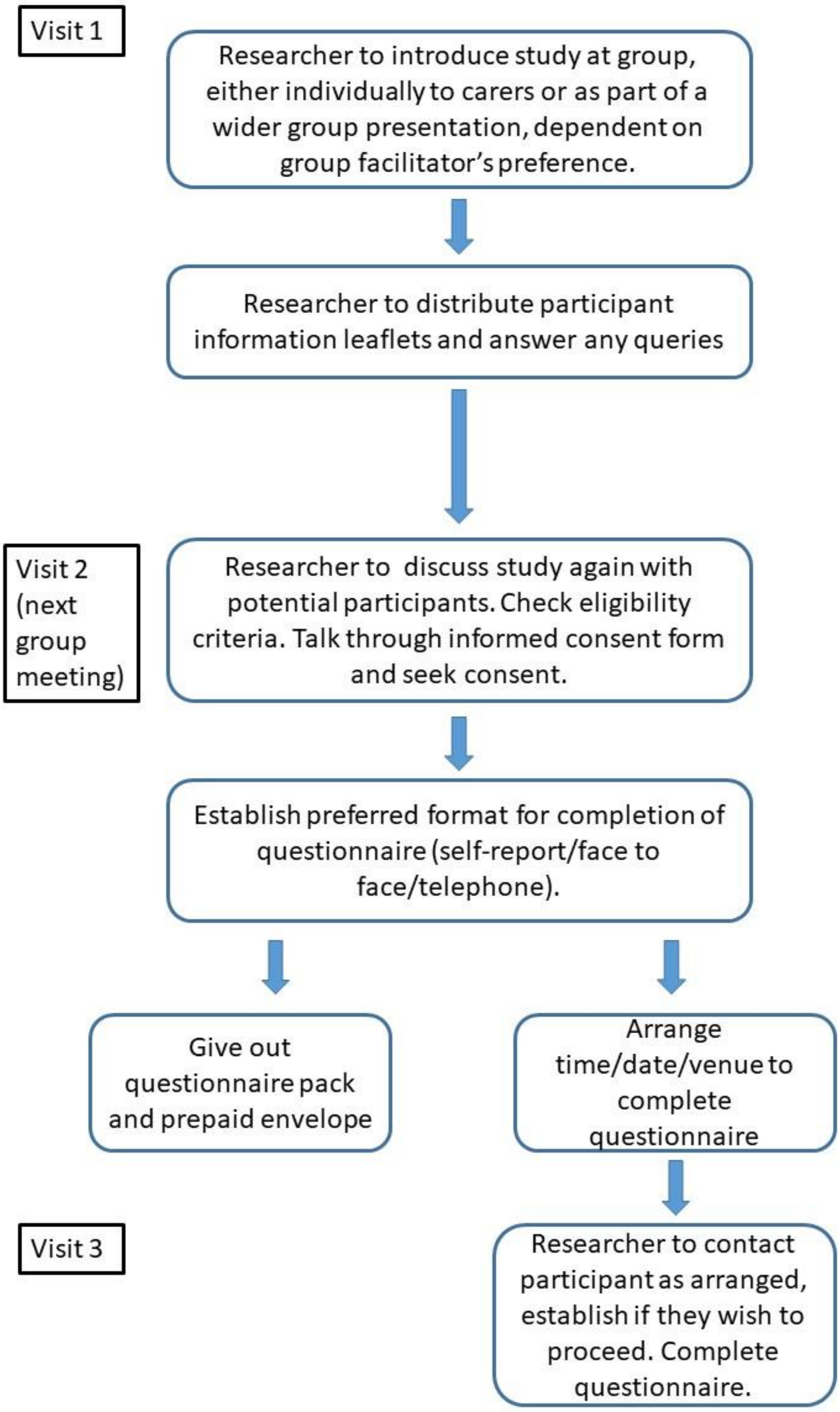


**Figure 3-2** Procedure for face-to-face recruitment at a Dementia Café or support group

Alternatives to face-to-face recruitment were:

2. Mailing list invitation: for potential participants who did not attend a café or support group.  Partner organisations sent an invitation letter to carers in their records. This letter briefly explained the project and provided telephone and email contact details for those interested in taking part. This step ensured confidentiality as I did not need to access the membership lists of partner organisations. Carers received the invitation letter and decided whether they would like to have more information about the research and if so, they contacted me or Healthwatch at their convenience. A follow-up letter, email or telephone call then followed. Please see templates given in sections 12.5 and 12.6.

3. Online invitation: following an application for support from the Alzheimer's Society I was able to post adverts on their online forum, Talking Point. The advert gave brief details of the project and my contact details. Interested carers then emailed me and I sent them the participant information sheet.  A follow-up email was sent after seven days, as shown in Figure 3-3.

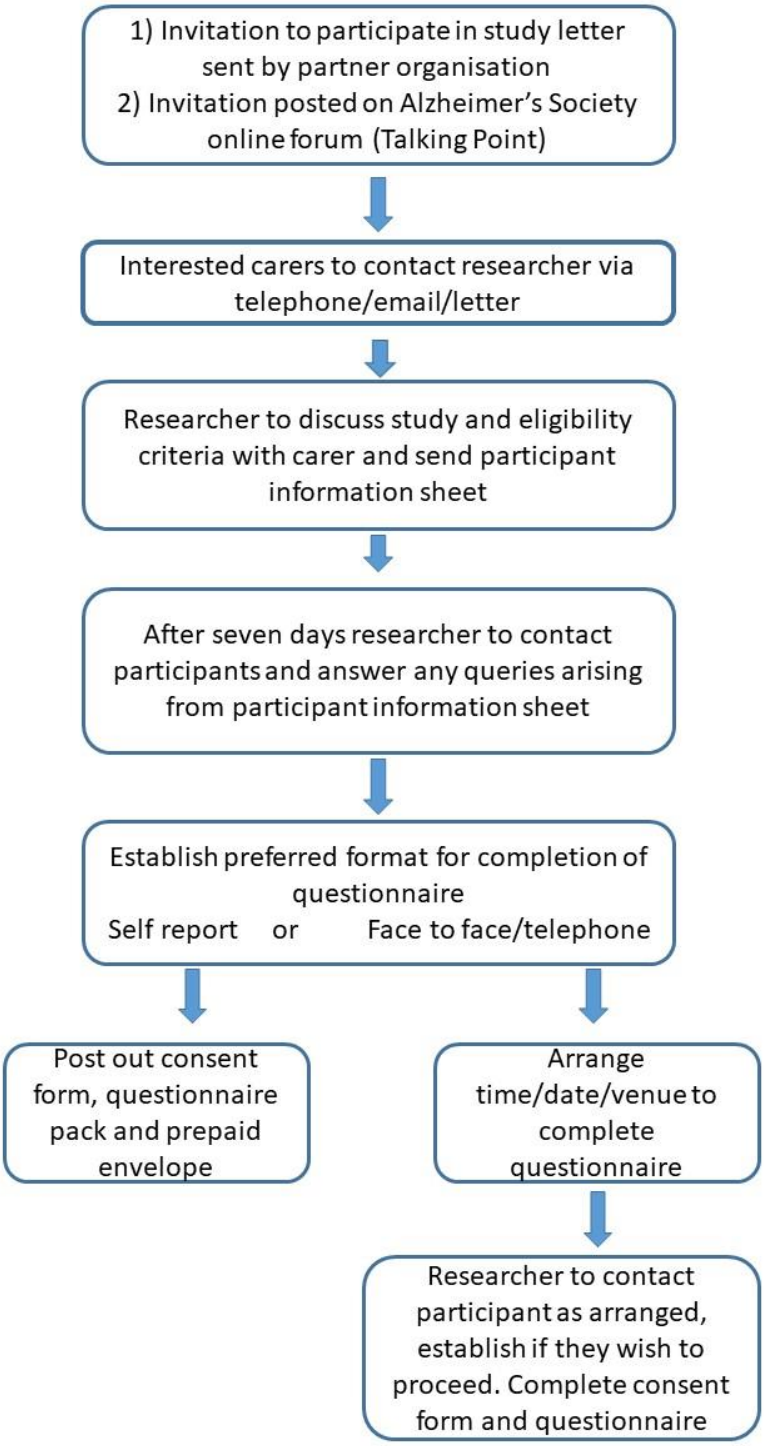


**Figure 3-3** Procedure for recruitment via partner organisations or Talking Point online forum

These three approaches – face to face, online and via mailing list – were used in an attempt to capture a representative sample including hard-to-reach carers such as those in employment who may not be able to attend events in the week and those with mobility or transport difficulties who may struggle to leave their home. An alternative approach would have been to use the Quality Outcome Framework (QOF) Dementia registers held by general practitioners. It was decided not to use this approach as the QOF dementia register identifies the person with dementia and not necessarily the carer, especially where the carer is a friend not a relative.

## 3.7 Phase one: Quantitative data collection

*Development of the survey*

Self-completed questionnaires are commonly used research tools. They have a number of advantages, specifically that they are inexpensive to administer and preserve the anonymity of respondents (Setia, 2016). However, alongside these strengths, questionnaires have limitations as response rates may be low, data may be compromised by missing answers and people may not be motivated to complete the questionnaire unless they feel it has specific relevance to them (Gillham, 2000). Simmons (2001) suggests that the completion of a questionnaire is significantly influenced by its appearance.

As previously discussed within section 3.4, the survey was piloted by carers to check the accessibility and acceptability. This pilot provided valuable feedback from members of the study population regarding format and content. Changes made in response to this feedback included:

1) Wider spacing of questions
2) Use of colour to differentiate questions
3) Use of bold font to highlight key words in the instructions.

Feedback was also received from the lay member of the Ethics Committee, who commented on the information and wording used on the front page of the survey. Hayes (2000) suggests starting surveys with general questions before moving onto specific questions. The carers who gave me feedback felt that some questionnaires were more challenging than others; for example, the Zarit Burden Interview (Zarit et al 1980) raises sensitive issues of anger and guilt. In response to this feedback, the order of the questionnaires in the survey was reviewed. In the final version, wellbeing and resilience questionnaires were placed first. Scales measuring depression, anxiety, stress, and burden followed, and questions about the person with dementia were placed at the end of the survey.

The survey was divided into three sections (see Appendix 12.7):

Section 1: This section included questions about the socio-demographic characteristics of the carer, their caring role, and brief details about the person with dementia. In addition, this section asked about attendance at community groups and the use of health and social care services.

Section 2: This section related to the carer and included questionnaires to measure wellbeing, resilience, social support, depression, anxiety, stress, and burden.

Section 3: This section related to the person with dementia and included two questionnaires measuring neuropsychiatric symptoms and activity of daily living skills. Details of the specific questionnaires are given in Table 3-2.

A note of thanks was included at the end of the survey and respondents were invited to volunteer to participate in further research by completing a form, which was subsequently detached from the survey.

### *Questionnaires*

Seven standardised questionnaires were used within the survey; details are given in Table 3.2. Cronbach alpha scores were calculated for the total sample (n=111).

| *Domain assessed* | *Questionnaire* | | *Cronbach Alpha score* |
|---|---|---|---|
| *Subjective wellbeing* | Personal Wellbeing Index-Adult (PWI-A) (International Wellbeing Group, 2006) | The PWI-A is a two-part questionnaire. The first question asks ‘How satisfied are you with your life as a whole?’ The second section breaks this down into its component parts, asking respondents to rate their satisfaction in eight areas: standard of living, health, personal achievement, relationships, feeling safe and part of a community, future security, and spirituality/religion. Participants rate their satisfaction with each item on a 0–10 Likert scale ranging from ‘completely dissatisfied’ (0) through ‘neutral’ (5) to ‘completely satisfied’ (10). The scale has been shown to have acceptable reliability and validity (International Wellbeing Group, 2006). | 0.915 |
| *Resilience* | Brief Resilient Coping Scale (BRCS) (Sinclair and Wallston, 2004) | The four-item scale asks respondents if statements apply to them. Answers range from ‘does not describe me at all’ through to ‘describes me very well.’ Statements cover creative responses to difficulties, emotional regulation, personal growth and replacing losses encountered in life. Scores can range from four to 20. Scores above 17 indicate ‘high resilient copers’. Normative data for the BRCS are available (Kocalevent et al. 2017). | 0.889 |
| *Perceived social support* | Medical Outcomes Study-Social Support Survey (MOS-SSS) | This questionnaire includes a four-domain scale of social support: emotional/informational support, tangible support, positive social interaction support, and affectionate support. Social support is graded with a five-point Likert scale ranging from never (0) to nearly always (4) with higher scores denoting a higher degree of perceived social support. The MOS-SSS measures the frequency of support the participant feels is available to them; it | 0.971 |

| | | | |
|---|---|---|---|
| | (Sherbourne and Stewart, 1991) | does not measure the objective level or location of support, i.e. the number or relationship of people within an individual's social group. As such, support can come from a single person or a wider community network. The tool has previously been used with dementia carers (Han et al. 2014). | |
| *Psychological distress* | Depression Anxiety and Stress Scale (DASS-21) (Lovibond and Lovibond, 1995b) | The Depression Anxiety and Stress Scale (DASS-21) was used to assess psychological distress. The DASS-21 is a well-established measure of negative affect in adults and has been used in studies of family carers (Kumfor et al. 2016; Ervin et al. 2015; Wong et al. 2019). It is a self-report measure that distinguishes between stress, anxiety and depressive states (Lovibond and Lovibond, 1995a). The DASS-21 is an effective and valid measure of psychological distress (Crawford and Henry, 2003). The scales were analysed separately in this research to give a distinct score for each domain: depression, anxiety and stress. Each scale comprises a seven-item Likert scale with statements such as 'I found it hard to wind down' having scores ranging from did not apply to me at all (0) to applied to me most of the time (3). | 0.926 |
| | Zarit Burden Interview Short Version (ZBI) (Zarit et al. 1980) | The Zarit Burden Interview (ZBI) (Zarit et al. 1980) is a widely used measure that identifies burden in dementia carers, evaluating psychological distress, disease impact on quality of life, social and family relationships. The short version contains 12 items and was used here to reduce the time the participants spent completing the questionnaire. Items are scored on a five-point Likert scale ranging from never (0) to nearly always (4). Higher scores indicate greater burden. The short version is a robust, reliable measure that produces comparable results to the full version (Bédard et al. 2001). | 0.839 |

| | | | |
|---|---|---|---|
| *Dependency* | Bristol Activities of Daily Living Scale (BADLS) (Bucks et al. 1996) | The assessment is a carer-rated questionnaire consisting of 20 daily-living activities developed in collaboration with carers of people with dementia. Carers are asked to rate the person with dementia's average ability over the previous two weeks. Scores can range from no help required with the particular activity (0) to unable to complete the activity even with supervision (3). This creates a score range of zero-60, with higher scores indicating greater dependency. In addition, carers can choose to score an item as not applicable if the person with dementia never engaged in that activity when well, for example housework/gardening. These not applicable items are scored zero. | 0.862 |
| *Neuropsychiatric symptoms* | Cambridge Behavioural Index-Revised (CBI-R) (Wear et al. 2008) | The Cambridge Behavioural Inventory Revised (CBI-R) is a carer-reported behavioural questionnaire that has been extensively used in studies involving people with dementia (Kumfor et al. 2018; Fernandez-Martinez et al. 2016). It comprises 45 items assessing the patient across ten domains (subscales: memory and orientation, everyday skills, self-care, abnormal behaviour, mood, beliefs, eating habits, sleep, stereotypic and motor behaviours, and motivation). For each question, the behaviour is rated on a five-point scale (never (0), a few times per month (1), a few times per week (2), daily (3), and constantly (4)), with higher scores indicating higher frequency of behavioural symptoms. | 0.954 |

**Table 3-2** Overview of questionnaires used in survey

*Limitations of questionnaires*

Limitations of specific questionnaires are discussed within the chapters where they are used, e.g. limitations of the MOSS-SSS are explored within Chapter 8. A summary of the limitations of the collection of questionnaires is given here. All the questionnaires used in the survey were self-reporting. No attempt was made to triangulate this data; the carers' perceptions of their wellbeing and the needs of the person with dementia are not challenged or verified. This gives a subjective view that may be influenced by social desirability response bias (Van de Mortel, 2008). This limitation is further discussed in section 10.5.

The BRCS and other scales used are positively worded. This creates the potential for 'acquiescence or extreme response' bias. In acquiescence bias, respondents may agree with all or nearly all of the statements and in extreme response bias, the respondents consistently score themselves at either end of the scale (Friborg et al. 2006). As higher scores on the BRCS indicate greater resilience, if acquiescence bias is a significant factor this may lead to results that do not necessarily reflect the true level of resilience in the sample, giving instead a higher than expected value. An alternative approach would be to use questionnaires that include both positively and negatively worded items, making respondents who are actively engaged with the questionnaire disagree with some statements. However, this can reduce internal reliability and exacerbate difficulties for respondents in interpreting the questions (Sauro and Lewis, 2011). Therefore, the questionnaires within this survey were chosen for their relevance, validity and accessibility.

There are other limitations due to the combination of questionnaires chosen. The questionnaires use different time frames, e.g. the BRCS asks the person how they feel generally whereas the DASS-21 asks specifically about feelings in the last week and the PWI-A uses the phrase 'at the moment'. Moving between these different temporal instructions may have presented a challenge to some carers.

The questionnaires were designed to be completed independently but five participants who expressed a wish to take part in the study were unable to complete the survey in the presented format due to sensory or physical impairment. For these carers, I completed the survey in a face-to-face interview at a time and setting of the carer's choosing, either at the University or their home.

Alternative questionnaires were considered, specifically the Adult carers-quality of life questionnaire (AC-QOL) (Joseph et al. 2012) and the Carers Needs Assessment Tool (CSNAT) (Ewing et al. 2015). Both of these have been co-developed with carers so would have been appropriate for this carer-focused research, but the AC-QOL focuses on care-related quality-of-life issues and the research questions within this thesis looked at broader aspects of overall subjective wellbeing. The CSNAT is not an outcome measure but a needs assessment tool to enable support needs to be identified and addressed, and having the carer identify their needs was not the focus of the thesis.

## 3.8 Phase one: Quantitative data analyses

IBM SPSS (24) (IBM Corp, 2017) was used for all statistical data analyses. Details of the specific analyses undertaken are described in the relevant chapters. A summary of analyses is given below:

- Cronbach's α was used to test the internal reliability of all questionnaires.
- Descriptive statistics were used to describe the samples.
- Categorical differences in the demographic profiles of participants were estimated using Chi-square tests.
- Kolmogorov-Smirnoff tests were used alongside visual examination of the distribution to assess the normality of the data.
- Spearman rank correlation analyses were performed to exclude potential multicollinearity among variables.
- Group comparisons were made using Mann-Whitney U tests, independent t-tests and One-way ANOVA where appropriate.
- Details of the effect sizes analyses are given in each chapter.
- Mediation analyses were undertaken using the PROCESS (Hayes, 2018) add-in for SPSS (Chapter 6).
- Logistic regression analyses were undertaken in Chapters 7 and 8.

The threshold for significance was set at $p<0.05$ and 95% confidence intervals are given to provide additional information of the range of values beyond simply identifying statistical significance.

## 3.9 Phase one: Steps taken to reduce bias in the quantitative data

There are a range of potential sources of bias within the design of a cross-sectional survey; this section describes the steps taken to address these.

*Sampling bias:* The participants were mainly approached via carer support services and this may have excluded carers who are not in contact with any form of service. Collaborating with Healthwatch gave me the opportunity to attend wider community events to publicise the study to people who may not attend dementia-focused settings, such as Dementia Cafés. Another potential source of bias was the format of the survey; this was primarily a postal return handwritten survey that required people to be literate, be able to write and have access to a post box. In an attempt to reduce bias, encourage wider participation and avoid discriminating against people with sensory or physical disabilities, carers were offered the alternative options of completing the survey over the telephone or face to face.

*Non-responder bias*: This was a challenge as it was not possible to ascertain why people chose not to participate if they were invited, i.e. it would not have been appropriate to quiz Dementia Café attendees about why they chose not to complete the survey. The limitation of not being able to compare the characteristics of non-responders with those of responders is highlighted in the overall limitations section 10.5.

*Self-selection bias*: This occurs when survey respondents are motivated to participate by their interest in the topic under investigation (Olsen, 2008). The potential for participants recruited via the Dementia Café network to take part in the belief that it would help to keep Dementia Cafés open was considered. Steps were taken to ensure that participants knew the purpose of the research was not to ‘build a case’ for funding but that the findings would be shared with local stakeholders.

*Misclassification bias*: The potential for misclassification bias was considered, and to this end survey questionnaires were chosen for their reliability and validity. Choosing internationally recognised tools that have been previously used in similar population groups aimed to ensure that the results were relevant to the target population and measured the phenomena under study.

## 3.10 **Missing data**

Steps were taken within the survey design process to attempt to minimise the likelihood of missing data. On the advice of the Patient and Public Involvement representatives and following feedback from carers who piloted the questionnaires and the lay member of the Ethics Committee, the following changes were made:

1) Colour and shading were used to differentiate questions
2) Additional spacing was added between questions and sections
3) Key instructions were typed in bold
4) Questionnaires were presented in order of priority, so if a participant chose not to complete all the questionnaires some analysis may be possible.

Missing data were assumed to be at random and were treated as such. Where questionnaire authors gave instructions for the handling of missing data, these were followed. For example, up to one missing item for each subscale of the DASS-21 was considered acceptable; more than one and the validity was considered compromised (Lovibond and Lovibond, 1995b). Where more than one missing item occurred, list wise deletion was used. Data from one survey were completely excluded as the participant had only completed section one of the survey

No data imputation was undertaken. A threshold of 5% missing data per questionnaire was set based on Schafer (1999), who maintains that this level of missing data is acceptable. All questionnaires met this threshold except the Bristol Activities of Daily Living (ADL) scale (Bucks et al 1996) and the Cambridge Behavioural Inventory Revised (Wear et al 2008), which had significantly higher rates of missing data, 13.5% and 15.5%. This limitation is further discussed in section 10.5.

## 3.11 **Phase two: Qualitative studies**

*Recruitment*

A total of 111 carers took part in the quantitative phase of the research. Of these, 37 agreed to be contacted about further studies. For the qualitative phase, a target sample of 12 participants was set. This was based on Guest et al’s (2006) findings that when interviews are suitably structured, the participants are similar in terms of experience of the area of interest (e.g. dementia care), the focus of the study is specific (e.g. resilient coping strategies) and the goal is to explore central themes, data saturation can be reached in as few as 6–12 interviews.

A purposive sampling frame was used to structure recruitment. A list of potential variables that may influence resilient coping was identified from the literature and survey data and was entered into a matrix (Appendix 12.12). These included socio-demographic characteristics and factors related to the context of caring. The quantitative phase of the research used the Brief Resilience Coping Scale (BRCS) (Sinclair and Wallston, 2004) to provide a measure of resilience. Carers were recruited from each resilience level as defined by the BRCS: low, medium, or high. Participants were also recruited on the basis of their age group and employment, and the level of dependency of the person they cared for. This ensured that the participants came from a range of socio-demographic backgrounds and had a variety of caring experiences. This strategy prevented interviews being dominated by one population group.

Consideration was given to determining when to stop data collection; achieving data/theoretical saturation is often stated as the reason to cease collecting new data (Caelli et al. 2003). However, nursing disciplinary approaches require that despite the number of incidences of any one phenomenon a practitioner may have seen, the nurse must assume that each person’s experience will be unique. Therefore, adhering to this focus on being person-centred and ‘saturation’ being considered to be in opposition to sound nursing orientation (Thorne and Darbyshire, 2005), an alternative approach was sought. Thorne et al. (2015) suggest that the decision to stop data collection should be based on a disciplinary understanding of the issue being studied and the needs of the target audience. In this instance, the range of carers recruited represented a diverse spectrum of experience and although it is not possible to say that all experiences and perceptions of resilience may be included, the data obtained from a sample of 13 carers were of sufficient depth and quality to meet the aims of the analysis. A summary of participant characteristics is given in Chapter 4.

*Study design*

Phase two used a qualitative design to explore three research questions

RQ1. How do carers conceptualise resilience? (Chapter 5)

RQ6. How does carers' perceived level of resilience compare with the level of resilience when measured on a standardised tool? (Chapter 5)

RQ7. What resilient coping strategies do carers use to overcome caring challenges? (Chapter 9)

Rather than adding free-text questions to the survey in phase one, I used face-to-face semi-structured interviews to elicit the participants' views and experiences about these issues. The interviews allowed for unanticipated ideas to be pursued with the participants during data collection so that factors underlying resilient coping could be explored inductively within the dataset. This method was also adopted over other qualitative data collection methods (e.g. focus groups or telephone interviews) because it was considered more appropriate to give the participants opportunities to discuss their views and experiences individually. This was because questioning was anticipated to reveal positive and negative experiences and views of the participants, which they may not have been comfortable discussing with other carers. Using telephones as opposed to conducting face-to-face interviews is acknowledged to support cost-effective sampling and access to hard-to-reach individuals, and to enhance participants' perceptions of anonymity during the interview (Sturges, & Hanrahan, 2004). However, the content of the phase two interview, i.e. describing struggles and how the individual copes with caring, could be considered sensitive, and therefore sharing such information about oneself may be distressing or cause 'emotional turmoil' (Drury et al. 2007). Face-to-face interviews present good opportunities to assess the participant's mood and wellbeing through the observation of their non-verbal language (Sturges and Hanrahan, 2004). They also enable the researcher to respond sensitively. Given that the planned sampling approach involved recruiting people with a variety of caring experiences, and that the interviews aimed to allow the participants to speak candidly about potentially upsetting experiences, this method was deemed most appropriate.

Specific data analysis strategies for each qualitative research question are given in Chapters 5 and 9. The overarching methods for phase two, the qualitative data collection and analysis, are summarised in Figure 3-4.

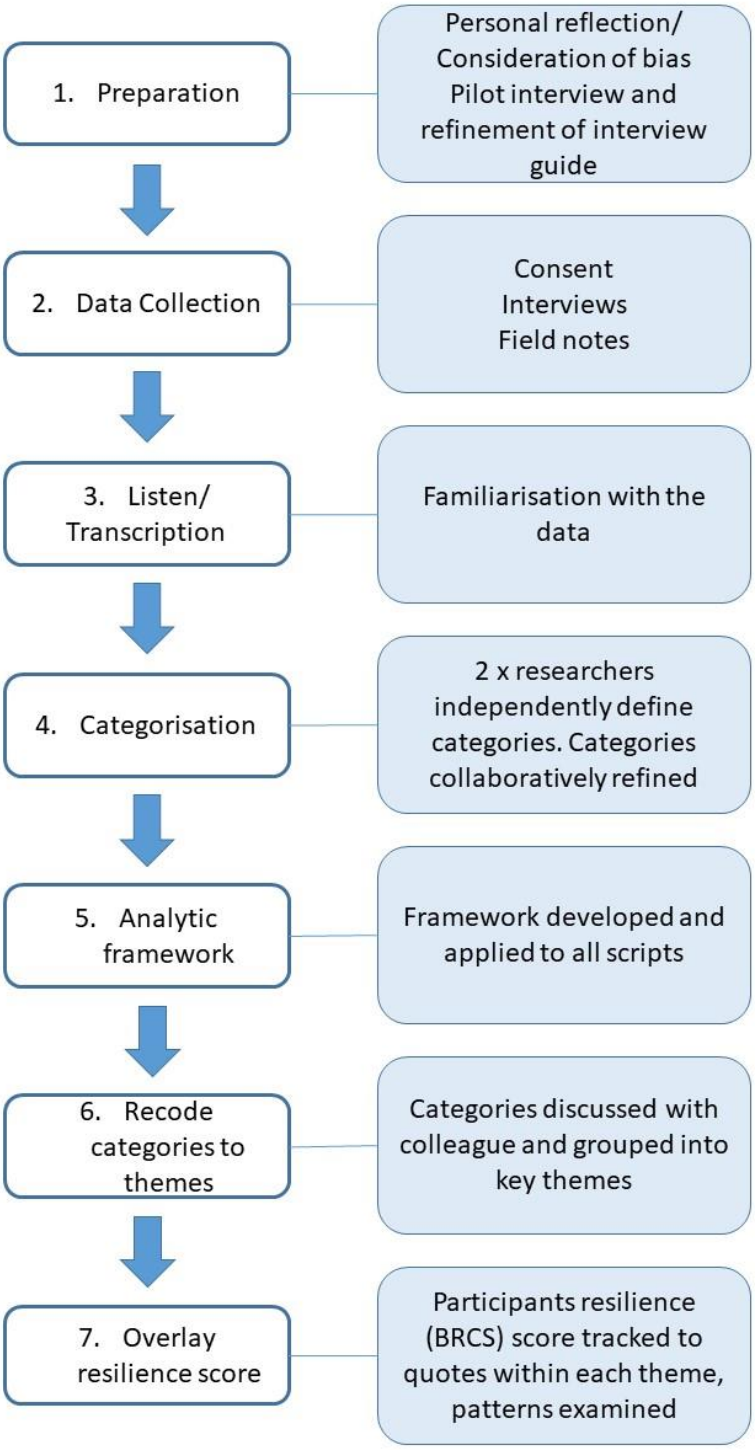


**Figure 3-4** Qualitative phase flowchart

The first step of the research design was the preparation phase, which began after I had gained ethical approval, and involved me reflecting upon my own experiences, ideas and biases. An extract of the reflective log is included as Appendix 12.15. This personal reflection gave me the opportunity to recognise my own disciplinary background, which I could build upon by conducting the research (Thorne, 2008).

Pilot interview

Initially, a pilot interview was conducted to assess the accessibility of the questions and to flag up any potential difficulties. A colleague who has experience of both undertaking research and caring for a relative with dementia kindly volunteered to participate in the pilot interview. She gave feedback about the order of the themes and ways to explore key terminology. This information helped to refine the interview schedule.

## 3.12 Phase two: Qualitative data collection

The interview

Following the informed consent process, semi-structured interviews were conducted. All participants were informed that they could withdraw consent at any time and stop the interview, take a break if needed and ask any questions required to help them clarify any confusion or misunderstanding. The interviews were not prescriptive but encouraged the carer to describe resilience by drawing on their personal situation and life events, such as sharing the diagnosis with members of their social network. Interviews began with questions about the daily activities of the carer and the support they provided to the person with dementia. Each interview was bespoke to the participant as follow-up questions were derived from the ongoing dialogue. Questions were adapted to support the carers' understanding and participation. The role of the researcher was to provide an encouraging non-judgemental space (Thorne, 2016). This enabled the participants to explain themselves fully and resulted in rich, detailed descriptions.

The topic guide for the interviews (Appendix 12.11) was designed based on the results of the survey and literature review. It started with open-ended questions about the participant, the person with dementia and the type of care they provided. The interview then moved on to more focused questions about the carer's understanding of resilience and progressed to discussing the participant's resilient coping strategies. Semi-structured interviews were chosen as they offered flexibility to adjust questions to the individual carer, so specific areas of interest could be followed, and the order of questions adapted to suit the needs of the participants (Bryman 2016). Using open-ended questions enabled carers to freely express their personal thoughts and experiences of social support in their current situation. As resilience is situational and dependent on the individual’s personal and wider social resources, the interview questions were situational rather than abstract. For example, when a participant talked about attendance at a support group, further questions were asked about this in order to encourage detailed descriptions of their own experiences of the group’s potential role in supporting their resilience.

The participants were offered the choice to take part either at their home or at the university. Six carers were interviewed at home. Reasons given by participants for choosing the university as a venue included being able to combine the interview with other appointments locally and a home visit being too disruptive for the person with dementia.

Immediately after each interview, field notes were made to record observations and reflections. This provided an opportunity to enhance the raw verbal data with information about the non-verbal communication of the participant, the setting and my thoughts and sense of the interview. The interviews were audio-recorded and transcribed. I transcribed the pilot interview and all other interviews were professionally transcribed by an experienced transcriber. Software package NVivo 11 was used to support the coding, management, and analysis of the data.

## 3.13 Phase two: Qualitative data analysis

Data were analysed separately for each research question. Specific descriptions of each analysis are given within Chapters 5 and 9, and an overview is given here.

Data were analysed using thematic analysis, using an interpretive description approach. Interpretive description is designed to generate ways of understanding human experiences of health and disease to inform clinical practice. It has origins in nursing science where it is used to develop rigorous qualitative studies, using an analysis of the existing literature and the clinical expertise of the nurse researcher as a ‘foundational fore structure to a new enquiry’ (Schultz and Meleis, 1988; Thorne et al.1997). Interpretive description is designed to answer questions with a clinical application. It is described as a framework that guides researchers towards identifying pragmatic findings over theoretical findings when addressing clinical or applied research questions (Miciak et al. 2018). Interpretive description was the most appropriate methodology to answer the qualitative research questions in this thesis as it allowed me to incorporate my existing practice knowledge, the current evidence base and new research findings. It has also been identified as particularly suitable for studies that draw on both qualitative and quantitative data and has particular value in taking the findings of applied research forward into clinical practice (Thorne, 2016).This approach was considered most suitable as the data synthesis of phase one and phase two seeks to build on the ecological theory of resilience, operationalise the resilience framework (Windle and Bennett, 2011) and identify its relevance to health and social care practice.

Alternative approaches were considered. Given the established theoretical basis for the resilience framework, a grounded theory approach was not appropriate as this research does not aim to discover new theory but rather to describe and make sense of the experience of resilience in dementia care, and relate this to the existing theory. Qualitative description was also considered, but this approach was rejected as the aim of qualitative description is to provide a 'rich straight description of an experience or event' (Neergaard et al. 2009). This analysis aimed to develop concepts and analyse data in a reflective and interpretive interplay with existing resilience theory and apply this within the context of dementia care.

## 3.14 Phase two: Steps taken to reduce bias in the qualitative analyses

Purposive sampling and the sampling matrix described in section 3.11 contributed to reducing bias in the sample by ensuring a diverse range of carers were invited to participate. Interpretive description does not prescribe a specific data analysis strategy; instead when designing a study, Thorne (2015) suggests that researchers should consider the range of factors that could influence clinical practice, including current evidence, nursing's 'moral mandate' and the current health care environment. The analyses in this thesis used an analytic framework. The framework was developed in collaboration with another research nurse. Initially, categories were identified independently of each other. Lists of categories were then discussed and adjustments made as needed. This process aimed to enhance the validity of categorisation and reduce the risk of researcher bias. These categories were grouped to produce a set of broad categories to populate the framework and apply to all scripts. Quantitative data from each participant's BRCS score was used in the final stages of each analysis to identify whether there were patterns within the data when the participants' responses were grouped by level of resilience.

A limitation of qualitative interviews with open-ended questions may be that the interview is led by the researcher's interests and opinions (Silverman, 2005). The use of interpretive description acknowledges the need for the researcher to recognise their own bias (Thorne et al 1997). Face-to-face interviews present a greater opportunity to collect rich data from non-verbal language and cues. However, this data may be misinterpreted, and the respondents may feel a 'social pressure' to give an answer they feel may be more acceptable to the researcher (Oltmann, 2016). The inductive approach to data analysis included periods of reflection between each participant interview. This helped to identify whether assumptions had shaped data collection. The use of a reflective log assisted in this process. Further details about types of bias resulting from the chosen methods are given in the limitations section of the general discussion, section 10.5.

## 3.15 Data synthesis of phase one and phase two data

Data synthesis aims to ameliorate the limitations of individual approaches by combining their strengths (Creswell and Clark, 2017; Hammond, 2005). However, a significant criticism and potential limitation of mixed-methods research centres on the ongoing debate of whether these diverse data can be effectively synthesised, or whether it is even appropriate to attempt to do so in light of the challenges of bringing different forms of data together (Sandelowski et al. 2006). It is therefore important to identify the aim of the synthesis, not so much whether data can be synthesised but how and why it should be done. In this research, the aim of data synthesis was to create a profile of 'a resilient carer' and operationalise the resilience framework (Windle and Bennett, 2011). It is hoped that this will support the understanding of the availability and use of personal and social resources that effectively promote carer resilience. The two-phase sequential design allowed general trends identified in the quantitative data to be explored further in a subset of the same population.

Data synthesis methods

The aim of the synthesis was to characterise the 'resilient carer', describing their mental health, social support and resilient coping strategies. The findings were then mapped to the resilience framework. A triangulation protocol is a process of gaining a fuller understanding of a problem by using different research methods (Farmer et al. 2006). The triangulation protocol shown in Figure 3-1 details how data was to be integrated. The quantitative data from the survey and the findings from the semi-structured interviews each explore factors that contribute to or threaten a carer's resilience, but from different perspectives. The findings were integrated using a data synthesis matrix (O'Cathain et al. 2010). The matrix facilitates the comparison of findings of different analyses to explore convergence, dissonance, complementarity, and silence (Farmer et al. 2006). Specifically, it highlights recurrent themes and any discrepancies or incongruence between data collected via different methods (Moffatt et al. 2006). This was appropriate for this research as it allowed the identification of the range of contexts in which carers provide care for the person with dementia.

The data synthesis matrix was built by first listing the findings from the various quantitative analyses. The findings from the qualitative analyses were then individually compared with the quantitative findings to establish whether they matched (convergence), supported (complementarity), disagreed (dissonance) or were absent (silence) (Farmer et al. 2006). Additional findings from the qualitative data were added to the mixed-methods matrix and data from the quantitative analyses were reviewed to identify whether these findings were reflected elsewhere. An extract of the synthesis matrix can be found in Appendix 12.14.

## 3.16 Summary

This chapter has given a detailed discussion of the considerations and design of the research. It has described the involvement of carers and stakeholders in refining the methods and data collection tools. The characteristics of the participant sample and implications for the study will now be considered in the following chapter.

# 4 PARTICIPANTS

## 4.1 Foreword

This chapter gives an overview of the total sample of carers who participated in phase one and phase two. The inclusion criteria were very broad; all participants were adults (aged over 18 years) providing care or support to a friend or family member with dementia. People who provided care on a formal/paid basis or to a person without dementia were excluded, as were those who were unable to complete the survey/interview in English.

First socio-demographic variables of carers are described in Table 4-1 and next Table 4-2 gives details about the context of the care they provided. Table 4-3 shows the socio-demographic characteristics of the people with dementia. Figure 4-1 shows the type of dementia of the person receiving care. Please refer to the participant characteristics in Chapters 5, 6, 7, 8 and 9 for specific information on the data included in each analysis.

## 4.2 Response rate

In total, 111 out of 150 surveys were returned (74%). It is not known how many people attended the presentations at Dementia Cafés, received an invitation letter or read the online advert but chose not to participate; 74% should therefore be considered the completion rate, rather than the overall response rate, as the denominator for the latter is unknown. This is further discussed in the limitations section 10.5. Data from one survey pack were excluded as only one section had been completed.

## 4.3 Carer characteristics

Socio-demographic characteristics are shown in Table 4-1. The majority of carers in the sample were female (66.7%), retired (73%) and caring for a spouse (61.2%). This is in line with expectations and reflects the profile of carers in the UK (Wimo et al. 2013).The under-representation of male carers and employed carers is discussed further in the limitations section in the general discussion. No carers under the age of 30 years completed the survey.

| **Characteristic** | | **n** | **%** |
|---|---|---|---|
| **Gender** | Male | 37 | 33.3 |
| | Female | 74 | 66.7 |
| **Age** | 30–49 | 6 | 5.4 |
| | 50–69 | 37 | 33.3 |
| | 70–79 | 42 | 37.8 |
| | 80+ | 26 | 23.4 |
| **Relationship to person with dementia** | Husband | 23 | 20.7 |
| | Wife | 45 | 40.5 |
| | Sibling | 2 | 1.8 |
| | Son | 3 | 2.7 |
| | Daughter | 20 | 18.0 |
| | Other | 14 | 12.6 |
| | Partner | 3 | 2.7 |
| | Missing | 1 | 0.9 |
| **Education** | Primary | 6 | 5.4 |
| | Secondary (up to 16 yrs.) | 40 | 36.0 |
| | A levels | 3 | 2.7 |
| | Vocational qualification | 30 | 27.0 |
| | Bachelor Degree | 19 | 17.1 |
| | Master’s Degree | 10 | 9.0 |
| | PhD | 1 | 0.9 |
| | Missing | 2 | 1.8 |
| **Employment** | Part-time/casual | 12 | 10.8 |
| | Full time | 9 | 8.1 |
| | Not working | 9 | 8.1 |
| | Retired | 81 | 73.0 |
| **Total** | | 111 | 100 |

**Table 4-1** Socio-demographic characteristics of carers

Information about the context of carer being provided is given in Table 4-2. Over 86% of carers identified themselves as the main carer of the person with dementia; 62.2% were providing full-time care, over 81 hours per week. Sixty-five participants attended a support group.

| | | n | % |
|---|---|---|---|
| **Carer type** | Main carer | 96 | 86.5 |
| | Secondary carer | 3 | 2.7 |
| | Joint carer | 11 | 9.9 |
| | Missing | 1 | 0.9 |
| **Care hours per week** | Less than 10 | 10 | 9.0 |
| | 11–20 hrs | 9 | 8.1 |
| | 21–40 hrs | 12 | 10.8 |
| | 41–80 hrs | 11 | 9.9 |
| | 81+ hrs | 69 | 62.2 |
| **Attended a carer support group** | No | 65 | 58.6 |
| | Yes | 43 | 38.7 |
| | Missing | 3 | 2.7 |
| **Total** | | 111 | 100 |

**Table 4-2** Context of care provided by participants to the person with dementia

## 4.4 Person with dementia characteristics

Person with dementia characteristics are summarised in Table **4-3**. The majority of people with dementia were living at home supported by a family member (75.7%). There were more men than women in this sample, which contrasts with national data, where 65% of people living with dementia are female (Prince, 2014). The over-representation of men in the sample of people with dementia may be due to the fact that most respondents were female carers looking after a male spouse.

| **Characteristic** | | **n** | **%** |
|---|---|---|---|
| **Gender** | Male | 63 | 56.8 |
| | Female | 45 | 40.5 |
| | Missing | 3 | 2.7 |
| **Age (years)** | 50–69 | 13 | 11.7 |
| | 70–79 | 41 | 36.9 |
| | 80+ | 55 | 49.5 |
| | Missing | 2 | 1.8 |
| **Residence** | Home alone | 14 | 12.6 |
| | Home with family | 84 | 75.7 |
| | Care home | 8 | 7.2 |
| | Deceased | 2 | 1.8 |
| **Years since diagnosis** | Less than 1 | 7 | 6.3 |
| | 1–3 | 54 | 48.6 |
| | 4–6 | 35 | 31.6 |
| | 7–9 | 8 | 7.2 |
| | 10+ | 4 | 3.6 |
| | Missing | 3 | 2.7 |
| **Total** | | 111 | 100 |

**Table 4-3** Person with dementia characteristics

The proportion of each type of dementia is shown in Figure **4-1**. Alzheimer's disease was the most common diagnosis (n=36, 32%). Sixteen participants left this question blank, indicating that the specific diagnosis may have been unknown to the carer.

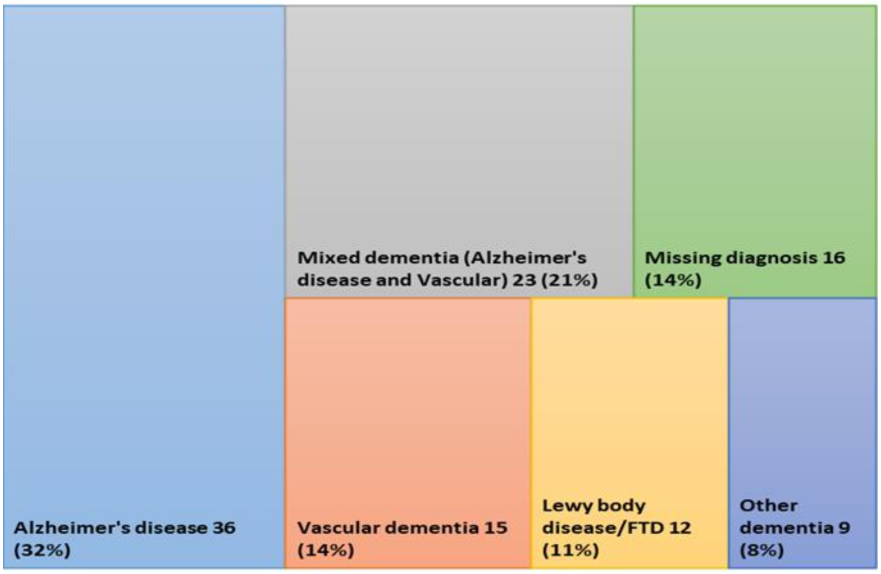


**Figure 4-1** Types of dementia of care recipients (n=111)

## 4.5 Phase two subsample

Thirty-seven of the participants from phase one (33%) agreed to be contacted about further research. Thirteen of these were recruited to the qualitative phase of the research, see Table 4-4.

| Pseudonym | Age | Gender | Employment | Resides with the PWD | Relationship to PWD | Type of dementia | Resilience (BRCS) |
|---|---|---|---|---|---|---|---|
| **Angela** | 72 | Female | Part-time | Yes | Wife | Parkinson's/ DLB | Low |
| **Pat** | 69 | Female | Retired | Yes | Wife | bvFTD/ PPA | High |
| **Theresa** | 65 | Female | Retired | Yes | Wife | Vascular | Low |
| **Evelyn** | 70 | Female | Retired | Yes | Wife | bvFTD | Low |
| **Daniel** | 65 | Male | Retired | No | Son | AD | High |
| **Bertie** | 81 | Male | Retired | Yes | Friend/ Housemate | AD/ Vascular | High |
| **Linda** | 65 | Female | Retired | No | Daughter | Vascular | Low |
| **Sandra** | 53 | Female | Full time | Yes | Wife | svFTD | Medium |
| **Mike** | 67 | Male | Part-time | Yes | Husband | bvFTD | Low |
| **Tuli** | * | Female | Full time | Yes | Daughter-in-law | Vascular | High |
| **Jean** | 69 | Female | Retired | Yes | Wife | AD/ Vascular | Low |
| **Denise** | 40 | Female | Not working | Yes | Daughter | AD/ Vascular | Medium |
| **Tom** | 73 | Male | Retired | Yes | Husband | AD | High |

PWD person with dementia, AD Alzheimer's disease DLB dementia with Lewy bodies, bvFTD behavioural variant fronto temporal dementia, svFTD semantic variant fronto temporal dementia, PPA primary progressive aphasia, BRCS – Brief Resilient Coping Scale. * - participant declined to answer

**Table 4-4** Qualitative phase participant characteristics

## 4.6 Reflections on the subsample for the qualitative analyses

The sampling strategy for the qualitative subsample aimed to identify a sample of carers with differing views and experiences. The diversity in the sample was sought so that carers with different socio-demographic characteristics, care experiences and levels of resilience were included. It was anticipated that this diversity would give a data set comprising various issues and views so that as many as possible different factors related to the research questions could be identified.

The subsample is broadly representative of carers nationally in some socio-demographic characteristics. In line with national statistics, 69% are women and 63% are retired; there was a slightly higher percentage of carers in paid work in this sample than the national average, 23% as opposed to 18%. A range of types of dementia was represented, including those where the primary need is not related to memory problems. This was important as carers of people with a young onset or rare form of dementia face unique and complex problems, different to those of carers of people with a late age onset dementia (Hvidsten et al. 2019). Only one carer was not a relative of the person with dementia, he described their relationship by saying, ‘he’s my buddy, we are housemates’. It is possible that other friends and housemates providing care for someone with dementia are not being recognised as carers, although they would have the same rights under the Care Act 2014 (HM Government 2014) as a family member who provides care. It is therefore important to understand the views of this group of carers as their experiences may be different to those of family carers. The majority of participants lived with the person with dementia. The lack of a remote carer, i.e. a friend or family member who is providing care from a considerable geographical distance, is a limitation of the sample for the qualitative analyses as they too may have different experiences of trying to navigate and access services. There is a lack of younger carers (aged under 30 years). One of the carers in this age group who had multiple caring responsibilities looking after both parents expressed an interest in the research. Unfortunately, due to several competing demands, she did not complete the survey or take part in the interview, and this section of the sampling matrix for the qualitative study remained unfilled.

## 4.7 Summary

This chapter has presented the socio-demographic and context of care characteristics of the participants. Overall, I had a good completion rate to the survey, although the response rate could not be calculated as there was no denominator available for this, and the planned sample size was not met. However a diverse range of carers took part in both the quantitative and qualitative phases. Limitations of the sample are explored further in the General Discussion. The next five chapters report the findings from the individual analyses. The first looks at carers’ conceptualisations of resilience and builds on the literature review in Chapter 2.

# 5 COPING BUT NOT ALLOWING THE COPING TO BE EVERYTHING: RESILIENCE IN CAREGIVING

## 5.1 Foreword

This chapter presents the first analysis of the qualitative data collected in phase two of the research (see Figure 3-1). It examines carers' conceptualisations of resilience and then compares them to definitions found in the published literature. In addition, the chapter also compares the carers' level of resilience as measured by the BRCS with how they described their own level of resilience during the interviews. Much of the content of this chapter was published as a research article in Health and Social Care in the Community (Jones et al. 2019b). In the article, details of the background and methods, which are given here in Chapter 2, were added.  The article did not include the specific commentary on the definitions of resilience derived from the literature search that is developed in this chapter.

## 5.2 Background

Resilience has been conceptualised as a dynamic and interactive phenomenon that is triggered by an antecedent event and developed through the interplay of risks and resources (Rutter, 2013). It is acknowledged that conceptualisations of resilience may vary between individuals, organisations and cultures, and that individuals may be more or less resilient in their response to adversities at different points in their lives (Southwick et al. 2014). Research exploring dementia caring and its impact on resilience has identified various risks and resources that may promote or hinder feelings of resilience (Windle and Bennett, 2011). However, only a few studies have focused specifically on the construct of resilience as determined by carers of people with dementia. A study that sought to obtain a carer-derived definition of resilience found that the participants had such difficulty with the question that it was dropped from the interview schedule and a definition was supplied by the researcher (O'Dwyer et al. 2017). An earlier study aiming to define resilience used a Delphi process (Joling et al. 2017) and included carers, but the statements that informed the process were again derived by the research team. The current analysis enables carers to share their own insights.

## 5.3 Research questions

The following research questions aim to further explore resilience from the carers' perspective. Bringing together the academic and lay understandings of resilience can add to the understanding of context-specific resilience definitions. These questions also provide an opportunity to explore potential resources that carers prioritised, separate to those identified in the resilience framework (Windle and Bennett, 2011). The first two questions are derived from RQ1 (see page 37); RQ1 was deconstructed as such in order to isolate the methodological steps required to answer it).

RQ1a) Do carers' conceptualisations of resilience vary from definitions found in the scientific literature?

RQ1b) What differences and similarities occur in in conceptualisations of resilience between carers with high, medium, and low resilience scores?

RQ6) How does carers' perceived level of resilience as described in an interview compare with their level of resilience when measured on a standardised tool?

## 5.4 Methods

The research questions above were addressed through qualitative methods. An overview of the data collection methods were given in Chapter 3. This section focuses on the collection of data for the first qualitative analysis. I conducted in-depth, semi-structured interviews with participants using Interpretive Description (ID) (Thorne et al. 1997) to explore carers' conceptualisations of resilience and compare these to the range of definitions found in the literature that have been either derived from studies of dementia carers or applied to this population. In this chapter, I bring together both the lived experiences of people looking after a person with dementia and a quantitative measure of resilience taken from their BRCS score in the survey to gain a more in-depth understanding of resilience in caring.

*Critique of definitions of resilience applied to dementia carers*

To answer RQ1a, a summary of resilience definitions identified from a scoping review of the dementia carer literature was prepared (Table 5-1). As discussed in Chapter 2, the definitions applied to dementia carers align with those used in other populations in that they vary in their understanding of resilience as a personality trait, a process, or an outcome. Of these three types, the use of outcome focused definitions, such as Luther et al's (1993) definition that resilience includes 'a return to previous healthy functioning' and Cherry et al.'s (2013) definition that resilience is 'the ability to maintain normal or enhanced functioning', may be the least helpful in this context. In a UK national survey of carers 72% of respondents reported that they had experienced mental ill-health, 61% reported new physical ill-health concerns due to caring and 58% believed that their health would continue to deteriorate (Carers UK, 2018b).

The focus on maintaining 'normal' or healthy functioning suggests that where the opposite occurs and the carer experiences ill-health and distress, this is due to a lack of resilience and so may be considered a failure on the part of the carer. This may place pressure on individuals to be seen to be 'thriving and succeeding' as in Cherry et al.'s (2013) definition. It also shifts the emphasis onto the carer to make the appropriate adjustments to facilitate their caring role, rather than this being a wider responsibility that includes service providers and others.

The definitions of resilience applied to this population do not consistently reflect the diversity of challenges individuals face when supporting someone with dementia. Joling et al. (2017) single out 'behavioural problems' as a challenge that requires resilience. O'Dwyer et al. (2017) highlight the potential for 'physical and psychological demands' to be placed on the carer. Other definitions use broad terms of 'adversity', 'stress' and 'trauma', without specifying what these may be.

None of the definitions found in the scoping review consider the temporal nature of resilience. Dementia carers often continue to provide care over many years (Adult Social Care Statistics Team, 2019) and the demands they experience may vary over that time, with periods of acute distress followed by relative stability (van Wijngaarden et al. 2018). Therefore, it is likely that resilience will also fluctuate, and the notion of a static resilient/not resilient dichotomy may be unhelpful in the dementia care context.

The definition most frequently cited in the literature was:

> *Resilience is 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 or "bouncing back" in the face of adversity' (Windle, 2011).*

This definition suggests that resilience is an active response by the carer, requiring them to respond flexibly to the challenges of supporting an individual with dementia. It emphasises the carer's social ecology and assumes they have access to people, structures and services that will support them. It does not take account of those carers who feel that they lack a support network. Recent research by Carers UK found that carers (of all groups, not specifically carers of people with dementia) were seven times more likely to say they were 'often or always lonely' than the general population (Carers UK, 2019). Windle's (2011) definition considers recovery central to resilience and that stress, trauma and adversity are prerequisites for a resilient response. The term 'bouncing back' appears frequently in resilience literature but it is not clear from the review what constitutes recovery in this context as resistance, adaption and recovery are used interchangeably to describe someone who 'manages' their situation in a positive way.

| **Year / Author / Paper** | **Definition** | **Participant / researcher defined** |
|---|---|---|
| Kobiske, K.R. et al. (2018) Resilience in caregivers of partners with young onset dementia: A concept analysis | Resilient caregivers exhibit attributes including determination, flexibility, positive thinking, self-efficacy, resourcefulness, social support, and spirituality | Researcher |
| O'Dwyer S. et al. (2017) In their own words: how family carers of people with dementia understand resilience | The ability to bounce back after a challenging situation; being able to recover from, resist, or adapt to the physical and psychological demands of caring | Researcher (this study originally aimed to derive a carer definition, but the study protocol was modified) |
| Joling, K.J. et al. (2017) What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination | Feeling competent to provide care as a carer, while facing substantial behavioural problems in the person with dementia | Delphi process including clinicians, academics, and carers |

| **Year / Author / Paper** | **Definition** | **Participant/ researcher defined** |
|---|---|---|
| Cherry, M.G. et al. (2013)<br>Factors influencing the resilience of carers of individuals with dementia | Resilience as a psychological conceptualisation is the ability to maintain normal or enhanced functioning during times of adversity and consists of two components: The first is thriving and succeeding, and the second is exhibiting competence in difficult situations or a situation where others often do not succeed | Researcher |
| Windle, G. (2011)<br>What is resilience? A review and concept analysis | '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 or "bouncing back" in the face of adversity' | Researcher |
| Norman, E. (2000) Resiliency enhancement: Putting the strengths perspective into social work practice | Resilience is identified as a characteristic or developmental process in individuals that, when activated, aids in thwarting the effects of social conditions that can lead to impaired daily functioning | Researcher<br>(Derived from mixed populations and subsequently applied to dementia carers) |
| Wagnild, G.M. & Young, H.M. (1993) Development and psychometric evaluation of the Resilience Scale | Positive adaption in the face of adverse life events | Researcher (Derived from older adult populations and applied to family carers) |
| Luthar, S.S. Doernberger, C.H. & Zigler, E. (1993). Resilience is not a unidimensional construct: Insights from a prospective study of inner-city adolescents | Resilience is a multi-dimensional construct, involving not only psychological traits, but also the individual's ability to use external sources to facilitate coping and return to a previous healthy level of functioning | Researcher<br>(Derived from human development studies and subsequently applied to family carers) |

| Year / Author / Paper | Definition | Participant / researcher defined |
|---|---|---|
| Rutter, M. (1990) Psychosocial resilience and protective mechanisms | “Resilience is the positive pole of the ubiquitous phenomenon of individual difference in people's responses to stress and adversity” | Researcher<br>(Derived from human development studies and subsequently applied to family carers) |

**Table 5-1** Summary of definitions of resilience derived from or applied to family carers of people with dementia

### *Data collection: Face-to-face interviews*

Interviews began with questions about the daily activities of the carer and the support they provided to the person with dementia. This provided both valuable context to the interview (Thorne, 2016) and helped to develop a rapport between the participant and the researcher. Next, the carers were asked how they would describe resilience. Some of the participants found giving a description challenging and the question was then rephrased to ‘What do you think a resilient person looks like?’ or ‘Do you know someone who is resilient, what makes you think they are resilient?’ Carers who were unable to conceptualise resilience as an abstract concept were able to give an answer when the question was grounded in their personal experience.

Finally, carers were asked whether they felt that they were resilient; again, this was difficult for some participants to answer. In these instances, the follow-up question ‘Are you surviving or thriving as a carer?’ was asked.

### *Data analyses*

The analyses ran in three phases. First, to answer RQ1a, (to explore discrepancies and congruency between definitions of resilience in the academic literature and carers’ own conceptualisations), the interview data were analysed using a framework approach (Ritchie et al. 2003). Interpretive description takes a ‘flexible approach’ that utilises intellectual enquiry, asking “why is this here?” “what does this mean?” (Thorne et al. 2004). This was important in this analysis to ensure that the contributions of each individual were explored fully before being considered as part of the whole.

Next, in response to RQ1b (to assess differences and similarities in conceptualisations of resilience between carers with high, medium and low resilience), the participants were grouped by their BRCS score and commonalities sought within these groups for each theme identified in the earlier analysis. Sub-themes were identified for low and high resilient carers. Finally, to answer the final question (RQ6), the carers’ response to the question, ‘do you think you are resilient?’ was compared to their level of resilience as measured by the BRCS. Potential reasons for any discrepancy were analysed.

## 5.5 Results

Research questions 1a and 1b

The findings for questions 1a and 1b are presented together under the overarching RQ1. Four themes were identified from the initial data analysis: i) the resilient response, ii) social support iii) self-compassion and iv) regarded as resilient. An overview of the carers' conceptualisations of resilience is given in Figure 5-1.

***Resilience is…***

***…knowing there is a solution to every challenge and believing you can find it.***

***…being flexible and adapting to new situations. Doing it differently is better than not doing it at all.***

***…a lifelong process of gathering skills, knowledge, and experience to create a buffer to protect you in times of challenge.***

***…fluctuating and has limits so be kind to yourself, celebrate your successes and do not dwell on the difficulties.***

***…not achieved in isolation, it's knowing when, and where to go for help – and persevering 'til you get it.***

**Figure 5-1** Summary of carers' conceptualisations of resilience

*The resilient response*

The literature highlighted that an antecedent event or adversity was required to trigger a resilient response in an individual. Carers considered both the diagnosis of dementia and the onset of care needs as significant antecedent events. When the carers were grouped by their BRCS scores and comparisons made between low and high resilient carers, there were marked differences in how they described their resilient response to these events. Low resilient carers conceptualised resilience as a passive response to challenge. Angela encapsulated this in her statement:

> *'Resilience is when you get so much crap thrown at you and it bounces off.'*

Evelyn considered it a survival trait:

> *'I think I am, [resilient] let's face it I'm still here to tell the tale.*'

Low resilient carers spoke of their resilience being determined by systems beyond their control and perceived that they had a lack of influence on the situation. Resilience was seen as being able to stay the course and 'keep going' despite ongoing challenges.

In contrast, highly resilient carers were less influenced by external factors, instead suggesting that having (and living by) particular values led to resilience. Pat referred to her 'doctrine', a set of values learned from her father, adopted herself and passed onto her children. She said resilience is knowing:

> '*For every question that you've got, there's got to be an answer, it's just a matter of finding it'*.

Bertie, too, felt that the wartime values instilled in him defined his resilience:

> *'Make do and mend, get on with it, bite the bullet. Don't whinge. You don't sit down and say 'poor me,' you get up and do something else'*.

High resilient carers described an active resilient response. They described believing that they could control their response to challenges and influence the outcome of different situations. There was an acknowledgement that their lived experience and beliefs enabled them to respond in a resilient way to new situations.

*Social support*

Definitions of resilience found in the literature described the social ecology of the carer and the role that social support and resources played in supporting resilience. Carers in this sample reiterated this, although they identified that support was not always forthcoming or, if available, it may not meet their needs. Low resilient carers, such as Theresa, described having little or no support:

> *'I've just said to George, 'Look we're on our own, me and you kid, and we've just got to get our way through it'.*

This perceived lack of support was a common experience for low resilient carers but for some it was also described in terms of independence. One carer in particular saw her lack of engaging help from others as a strength that supported her feelings of resilience. In contrast, highly resilient carers saw resilience as being positively impacted by wider social connections and they included other people in their conceptualisation of resilience. Daniel highlighted that resilience does not work in isolation:

> *'A resilient person is maybe not a tough person. A resilient person is somebody who has a good network of friends and support'.*

Participants who shared their caring responsibilities with another relative described how this promoted their resilience. Tuli and her husband cared for her mother in law:

> *'If it was one of us, it wouldn't have worked. Absolutely no way'*.

However, carers also discussed the challenges that support networks can bring, especially where there is disagreement within a network over the best way to support the person with dementia. This was particularly pertinent for those who cared for friends, or where there had been previous estrangement within a family. They described how remote relatives placed demands, expectations, or restrictions on them, which impacted their ability to be resilient.

Highly resilient carers described how resilience was having the skills, confidence, and perseverance to engage with their support network for the benefit of themselves and the person with dementia. Tom encapsulated the negotiation and emotional regulation skills required:

> *'Resilience is giving and taking in some form. I think you are flexible and give and take, and where you are wrong, admit you are wrong. I don't let anything wind me up.'*

Acting as an advocate for the person with dementia was seen as important for promoting resilience. Carers described being more likely to be 'resilient for' the other person, persevering more with securing services for them than they would have done for themselves.

### *Self-compassion*

Notably, there were no references specifically relating to self-compassion in the definitions found in the literature. Carers described how they had grown into resilience and how being resilient was a process. Being in the moment, just dealing with the ‘now’ and being self-compassionate were important aspects of becoming resilient. Pat suggested resilience was,

> *‘Doing what you can, if there’s something you can’t do, don’t do it or do it differently, look for the positives, don’t beat yourself up.’*

Tuli concurred,

> *‘I realised there are things you can do something about or you can’t do something about. Do the best you can.’*

Carers described how self-compassion was important as resilience may fluctuate. Tuli described resilience as a buffer that protected her in times of stress, but one that requires nurturing.

> *‘I think everybody has a certain level of resilience, like a mattress but a good quality one or a not so good quality one but everyone has one. And if you have something that kind of protects it, say a bed frame – like social help, who recognise your mattress… your resilience, that’s great, but if not, if you are just bouncing on your mattress the whole time it rains and rains down and suddenly you find you have nothing left and you just crumble.’*

Other carers echoed the possibility that your resilience may desert you. For highly resilient carers this was tempered by the belief that recovery was possible. Bertie said:

> *‘Every so often I hit the buffers and the wheels come off. I’m totally and utterly exhausted and I can’t do any more [but] I’m just like a rubber ball: hit the deck and bounce back.’*

Being self-compassionate was described in terms of accepting personal limitations and adapting expectations. It was also linked to promoting resilience by having time away from the person with dementia. Mike said,

> *‘A resilient person is someone who copes, coping but not allowing the coping to be everything, not losing everything you used to have. Having a life which isn’t entirely devoted or overwhelmed by that [caring for someone with dementia].’*

This theme was common to both low and high resilient carers. It was not an easy process to accept one’s limitations, and it did not come naturally to some carers even where it’s importance was accepted. Mike (a low resilient carer) identified the importance of not being overwhelmed by caring but he continued to feel guilty when he went to work or took any time for himself. In contrast, high resilient carers were very open about their limitations and the need for a break from caring. They used day care services for their relatives so that they had time to pursue their own interests.

### *Regarded as resilient*

Discrepancies between being perceived by others as resilient and feeling resilient were not discussed in any of the definitions found in the literature. Carers in this sample said that other people judged their resilience, based on how much they took part in social activities such as going to a Dementia Café. Carers said that other people’s assessment of their resilience did not always match how they felt. Sandra said:

> *‘From the outside, you could look resilient, without actually being resilient. So you come across as if you just cope with everything but behind the scenes, you could be struggling.’*

For some carers, the outward appearance of resilience had potentially unhelpful consequences as others did not see their need for support. When Theresa was asked if she was a resilient person she said:

> *‘I don’t know, I don’t know. People say I’m a strong person but inside I’m not.’*

Angela did not feel that she was resilient but social services assessments had determined otherwise:

> *‘Social services said to me, this is the thing that really got my goat and this is a resilience thing – I was told I would have help <u>when</u> I hit a crisis.’*

She felt that the assessment process did not take into account how difficult her current situation was, and as she appeared to be coping, she was not offered any support. This was a more common experience for low resilient carers: all the carers who scored in the low range in the BRCS thought that others would consider them resilient. This belief came from either being denied services, as described by Angela, or comments and compliments they had received from friends, telling them how well they were doing. One carer felt that these compliments were used to discourage requests for help. Highly resilient carers described being less concerned about being seen to be resilient by others and therefore this was not a barrier to asking for help.

### Research Question 6

RQ6 examined and compared carers' perceived resilience, as described during the interview, with their level of resilience when measured on a standardised tool. When comparisons were made between the participants' interview answers and their rating on the BRCS, there were some discrepancies between the quantitative measures and interview responses, as shown in Table 5-2.

| Participant | BRCS | Self-assessment of level of resilience | Matched |
|---|---|---|---|
| Angela | Low | Low | Yes |
| Mike | Low | Low | Yes |
| Theresa | Low | Low | Yes |
| Jean | Low | Medium | No |
| Evelyn | Low | High | No |
| Linda | Low | High | No |
| Sandra | Medium | Low | No |
| Denise | Medium | Low | No |
| Daniel | High | Low | No |
| Tuli | High | High | Yes |
| Tom | High | High | Yes |
| Bertie | High | High | Yes |
| Pat | High | High | Yes |

Shaded rows indicate matching BRCS scores and self-assessment ratings

**Table 5-2** Comparisons between BRCS rating and carer's own rating of their resilience

Six of the thirteen carers had BRCS scores that matched their answers about how resilient they felt when they were asked during the interview. Three low-, two medium- and one high-scoring carer expressed levels of resilience that were not reflected in their BRCS score. Three of the carers who scored in the low range on the BRCS said that they felt that they were resilient people. Neither of the two carers who scored in the mid-range said that they were resilient; instead, they both said that they lacked resilience. The carer who scored the lowest possible mark on the BRCS said she was ‘thriving a little bit’ and one carer who scored in the high band said he did not feel resilient, describing himself as ‘surviving’. As described earlier, the three carers with low BRCS scores believed that people misjudged their level of resilience, but when the ratings carers gave themselves and the measured levels of resilience were compared, discrepancies were found for carers with low, medium and high BRCS scores.

## 5.6 Discussion

This chapter presents the first analysis of the qualitative data. Semi-structured interviews were used to answer three research questions: RQ1a) Do carers conceptualisations of resilience vary from definitions found in the scientific literature?; RQ1b) What differences and similarities occur in in conceptualisations of resilience between carers with high, medium and low resilience scores?; RQ6) How does carers’ perceived level of resilience as described at interview compare with their level of resilience when measured on a standardised tool?

This analysis has created a shared terminology of resilience, enabling the refinement of the understanding of dementia carer resilience. Differentiating findings by level of carer resilience as measured by the BRCS has illustrated the complexity of resilience and the heterogeneity of carers’ coping strategies. The findings for questions RQ1a and RQ1b revealed that carers’ conceptualisations of resilience reflect, in part, the characterisations found in the literature, namely positive adaption (Wagnild and Young, 1993), maintaining or regaining mental wellbeing following periods of adversity (Rutter 2006, Luthar et al 200, Masten 2001) and seeking support from wider social resources (Bennett and Windle, 2015). However, carers also prioritised self-compassion and identified with the experience of being both resilient and distressed.

These findings align with those of a Delphi study (Joling et al. 2017) which included family carers, researchers, and clinicians, and found that carers’ definitions and professionals' definitions varied. In line with my findings, carers in the Delphi study included mechanisms for being resilient within their overall definitions, prioritising maintaining a positive relationship with the person with dementia and viewing this as a descriptor of resilience. This confirms previous findings that both self-care and acceptance are key to carers' definitions of resilience (O'Dwyer, 2017). The current analysis extended self-care to focus on self-compassion, which included carers understanding their limits; disappointment and failure are part of life and should not be a source of self-criticism (Neff, 2012).

In contrast to the findings of the current analysis, some definitions found in the literature consider resilience and distress to be mutually exclusive, with the absence of distress being a defining characteristic of a resilient individual (Donnellan et al. 2015). However, O'Dwyer et al. (2017) found that carers in their study also described fluctuating levels of resilience dependent on a range of socio-cultural and environmental factors, and that resilience and distress could co-exist.

In response to question RQ1b, the findings show that there are some differences in how carers with low, medium, or high BRCS scores conceptualise resilience. Highly resilient carers are able to accept that there may be limits to what they can achieve in the face of supporting someone with a complex life-limiting illness: 'common humanity' and 'mindfulness' are elements of self-compassion (Neff, 2012). Highly resilient carers demonstrate common humanity as they are able to maintain social connectedness and integrate their experience with that of others. Mindfulness supports the carer to be able to accept and devise strategies to manage the current situation and live in the moment (Guichen et al. 2016). Acceptance has been shown to be important to carer wellbeing, with acceptance and commitment therapy (ACT) being particularly suitable for dementia carers (Losada et al. 2015) and having particular benefits in terms of reducing carer anxiety (Kishita et al. 2018).

Low resilient carers conceptualised resilience as a passive response to challenge. This may highlight the lack of self-determination some carers feel: their caring role dictates their world and resilience is necessary, if not desirable, as the alternative is to be overwhelmed, unable to cope and in 'crisis'. However, this experience may lead to an outward demonstration of resilience that masks the carer's distress.

Some carers in this sample struggled to define resilience. This is in line with other studies with dementia carers (O'Dwyer et al. 2017) and people with multiple sclerosis and their carers (Silverman et al. 2017). This is an important finding as the lack of consensus on the meaning of resilience in different groups of people hampers development of policy recommendations and bespoke interventions (Kolar, 2011). Differentiating between the consequences of and contributors to resilience was difficult in the analysis, as carers' conceptualisations were intertwined with their descriptors of 'being resilient'. Rather than focusing on ways to define resilience, it may be more useful for researchers to identify specific resilient coping behaviours in order to enable health and social care practitioners to better develop supportive interventions for carers of people with dementia.

RQ6 explored whether the measured levels of resilience reflected the participants' views of their own resilience. There is no gold standard tool for measuring resilience (Windle et al. 2011), and for this reason the present analysis used the BRCS (Sinclair and Wallston, 2004). The scale identifies four criteria for resilience: creative responses to problems, self-control, personal growth and replacing losses experienced in life. Definitions given by carers in this sample included but were not limited to these factors. The measured level of resilience using the BRCS did not consistently reflect the carers' own rating of their level of resilience as described during the interview. This may be attributed to the fact that characteristics considered by professionals to be suggestive of resilience, such as positive coping skills (Joling et al. 2017) and engagement with support services (Donnellan et al. 2015) are different to the criteria carers apply themselves. The potential consequences of being regarded as resilient by others were described by carers; how resilience is determined, i.e. whether the individual has made a positive adjustment, can be very subjective (Glantz and Sloboda, 2002). However, there is insufficient evidence on how this positive adaption is assessed in different groups and what impact these decisions may have for individuals and wider society (Kolar, 2011). Carers in the current research identified the difficulties they felt arose when their level of resilience was misjudged, describing how offers of help and assistance may be reduced based on that erroneous assessment. Interventions to support carers are often multi-component and designed to be delivered over a prolonged period (Elvish et al. 2013). The cost-effectiveness of providing such services to individuals who are considered to be resilient may be questioned, as they do not display overt distress or appear to be failing in their caring role (Luthar et al. 2000). The finding that some low resilient carers felt the need to mask their distress and appear resilient may be indicative of a wider social stigma associated with providing care for a person with dementia (Werner et al. 2012), which is associated with a lower uptake of services (Cations et al. 2017).

Limitations within this analysis must be acknowledged. As with all qualitative research, the findings are transferable rather than generalisable, although they align with other research in the field. A challenge and limitation of this analysis was the attribution of weight to the carers' reported level of resilience and the BRCS scores. It was decided to divide the group on their quantitative data scores rather than on their perceived level of resilience, as this facilitated meeting the aim of contrasting the carers' lived experiences and understanding of resilience with the research tool based assessment. Further limitations of the methods chosen are discussed in the General Discussion, section 10.5.

## 5.7 Conclusions and implications

The findings have demonstrated the potential inconsistency between the score achieved using a standardised tool, the carers' own rating of their level of resilience and the carers' perceptions of assessments made by health care professionals. This has implications for practice, as carers who are wrongly regarded as resilient may be disadvantaged by having fewer offers of help from family, friends, and formal services.

Incorporating the carers' descriptors of resilience, and the values, beliefs and behaviours that support their resilience may improve the validity of needs assessments. Bringing together needs assessments and resilience discussions may support the understanding of the carer's immediate needs, the impact of caring on the individual and whether they wish to continue to care. This wider approach enables health and social care practitioners to meet the statutory requirements placed on local authorities by the Care Act 2014 (HM Government, 2014).

The observation that highly resilient carers prioritise self-compassion as being key to resilience is relevant to healthcare professionals supporting carers who have lower resilience. They may benefit from interventions such as compassion-focused therapy (Gilbert, 2009) and acceptance and commitment therapy (Hayes et al. 2006).

The findings of the current analysis identified that resilience did not protect carers from distress. However, highly resilient carers discussed their ability to recover from setbacks. Carers in this sample described reactive, crisis-led services and needs assessments that did not reflect their caring goals. A policy focus on supporting resilience throughout the caring trajectory may aid the primary prevention of carer morbidity. Aligning assessments and the allocation of resources with the carer's priorities may support their resilience.

## 5.8 Summary

This chapter has focused on clarifying how carers understand resilience. This provides a valuable context for the next qualitative analysis in Chapter 9. The next three chapters focus on operationalising the resilience framework, through a quantitative analysis of the factors identified within the framework (Windle and Bennett, 2011). This starts with an analysis of psychological wellbeing from the individual level of the framework. The findings from this chapter have identified that carers described feeling both resilient and distressed. Chapter 6 specifically looks at the role of resilient coping as a mediator in the distress-wellbeing relationship.

# 6 THE ROLE OF RESILIENT COPING IN DEMENTIA CARER WELLBEING

## 6.1 Foreword

The previous chapters have explored the literature and carers' understanding of resilience in dementia care. This chapter explores one aspect of the 'individual' level of the resilience framework, namely, psychological resources. The analysis focuses on the relationships between psychological distress, resilient coping, and subjective wellbeing. The findings reported in this chapter have been published in the British Journal of Neuroscience Nursing (Jones et al. 2019a). This chapter describes the testing of two hypotheses: 1) carers with higher levels of resilient coping will report less depression, anxiety, stress, and burden; and 2) resilient coping will have a mediating effect on the relationships between depression, anxiety, stress, burden and subjective wellbeing. The outcomes of these analyses contributed to the characterisation of the 'resilient carer'.

## 6.2 Hypotheses

The analyses test the following hypotheses:

1) Highly resilient carers will report less distress than carers with lower resilience.
2) As carer distress increases, carer wellbeing will decrease, and the presence of resilient coping will mediate the relationship between carer distress and wellbeing.

A model indicating the potential role of resilient coping in the distress-wellbeing pathway is presented in Figure 6-1.

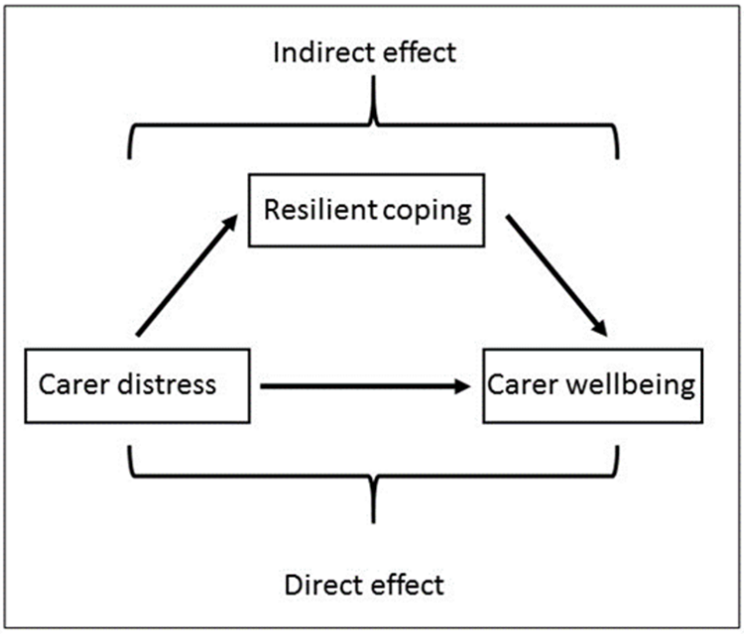


**Figure 6-1** Proposed model of relationship between carer distress and carer wellbeing with resilient coping as a potential mediator

## 6.3 Methods

*Participants*

Inclusion criteria: participants must be

(1) providing care to a friend or family member with dementia,

(2) aged 18 years or older, and

(3) able to complete a survey in English.

Exclusion criteria: paid carers, befrienders and volunteer carers were not included in this research.

The demographic variables investigated included carer gender, age group, relationship status, employment, education, and the number of hours spent caring each week.

The research was promoted through adverts in newsletters, carer information events held by local charities and an online carers' forum ('Talking Point', Alzheimer's Society UK). Data were collected between July 2016 and September

2017 via a self-completed postal survey. Recruitment strategies and consent procedures are discussed in section 3.6 and are shown in Figures 3-2 and 3-3.

*Questionnaires*

Carer resilience was assessed using the BRCS (Sinclair and Wallston, 2004). Psychological distress was measured using two scales, the Depression Anxiety and Stress Scale (DASS-21) (Lovibond and Lovibond, 1995b) and the Zarit Burden Index (ZBI) – Short version (Zarit et al. 1980). Subjective wellbeing was measured using the Personal Wellbeing Index-Adult (PWI-A) (International Wellbeing Group, 2006). Details of all these questionnaires are given in the methods chapter and shown in Table 3.2.

*Data analyses*

In order to compare the characteristics of carers according to their level of reported resilient coping, the sample was split into three groups as per the guidelines for the BRCS: high resilient coping (i.e. those with a score of 17 or above), medium resilient coping (scores 14-16), and those with low resilient coping (scores 4-13). Chi-square tests were then used to evaluate the categorical differences between the three groups of carers.

Marital status and co-residence have been shown to provide specific challenges and increase the potential for psychological distress in carers. For this reason, spousal carers were compared to non-spousal carers, and carers who lived with the person with dementia were compared with those who lived apart (O'Rourke et al. 2010).

Next, to identify differences in depression, anxiety, stress (DASS-21) and burden (ZBI) between the carers (split by levels of resilient coping: high, medium, and low), one-way ANOVAs with post-hoc tests were run. To verify whether the data were normally distributed, all carers' scores on the DASS-21 subscales and ZBI were plotted on histograms for visual examination. Kolmogorov-Smirnoff tests were used to assess normality. Stress and burden were both normally distributed. Depression and anxiety did not meet the assumptions of normality, however, with a sufficient sample size, the violation of this assumption should not cause significant problems for analysis (Elliott and Woodward, 2007). With this approach in mind, I proceeded with a parametric approach to the data analyses. Effect sizes for one-way ANOVA were calculated using $\omega^2$, where values of 0.01, 0.06 and 0.14 represented small, medium, and large effects respectively (Kirk, 1996).

Finally, to investigate the role of resilient coping as a mediator in the carer wellbeing–carer distress relationship, mediation analyses including all carers in one single group were conducted. Each distress variable (depression, anxiety, stress, and burden) was examined separately. The significance of the indirect effect of this relationship was measured using 1000 Bootstrapped samples 95% bias-corrected confidence intervals (95%BcaCI). Effect sizes were described using the completely standardised indirect effect (Elliott and Woodward, 2007; Hayes and Rockwood, 2017; Pallant, 2013). Bootstrapping was chosen over other mediation tests (such as the Sobel test) as it has been shown to be more effective for use with clinical data (Hayes and Rockwood, 2017). IBM SPSS Statistics 25 and PROCESS v3 (Hayes, 2018) software were used and statistical significance was set at $p<0.05$.

## 6.4 Results

*Characteristics of resilient carers*

Of the 150 mailed surveys, 110 were completed and returned (73%). As shown in Table 6-1, 23% (25/110) of the respondents had high resilient coping, 28% (31/110) scored in the medium range, and 49% (54/110) in the low range. There was a significant difference in gender between the groups; women reported higher resilient coping. There were no significant differences between carers with high, medium, or low resilient coping in relation to age group, education, relationship, residing with the person with dementia or number of hours per week spent caring.

| | **Low resilience BRCS ≤13 (n=54)** | **Medium resilience BRCS 14-16 incl. (n=31)** | **High resilience BRCS ≥17 (n=25)** | **Chi-square tests (n=110)** |
|---|---|---|---|---|
| Gender | | | | $X^2_{(1)}=7.11$, $p=.03$* |
| Male | 24 (44%) | 5 (16.1%) | 8 (32%) | |
| Female | 30 (56%) | 26 (83.9%) | 17(68%) | |
| Age group | | | | $X^2_{(2)}= 1.29$, $p=.86$ |
| ≤ 69 years | 19 (35.2%) | 12 (38.7%) | 11 (44%) | |
| 70-79 years | 20 (37%) | 13 (41.9%) | 9 (36%) | |
| 80+ years | 15 (27.8%) | 6 (19.4%) | 5 (20%) | |
| Education | | | | $X^2_{(2)}= 0.59$, $p=.96$ |
| Up to 12 years formal education | 23 (42.6%) | 14 (45.2%) | 9 (36%) | |
| Up to 14 years formal education | 15 (27.8%) | 9 (29%) | 8 (32%) | |
| 15 years + in formal education | 16 (29.6%) | 8 (25.8%) | 8 (32%) | |
| Relationship to person with dementia | | | | $X^2_{(1)} =1.56$, $p=.46$ |
| Spouse | 36 (66.7%) | 19 (61.3%) | 13 (52%) | |
| Other | 18 (33.3%) | 12 (38.7%) | 12 (48%) | |
| Person with dementia resides with family carer | | | | $X^2_{(1)}= 3.97$, $p=.13$ |
| Yes | 45 (83.3%) | 20 (64.5%) | 18 (72%) | |
| No | 9 (16.7%) | 11 (35.5%) | 7 (28%) | |
| Hours spent providing care per week | | | | $X^2_{(1)}= 3.51$, $p=.17$ |
| Up 40 hours | 11 (20.4%) | 12 (38.7%) | 8 (32%) | |
| 41+ hours | 43 (79.6%) | 19 (61.3%) | 17 (68%) | |

**Table 6-1** Carers demographic characteristics

The sample was split in regards to resilient coping scores: low (BRCS score 0-13); medium (BRCS score 14-16); and high resilience (BRCS score ≥17). Significant differences are highlighted in bold. $^*p<.05$

*Are reports of psychological distress different between carers with high, medium, or low resilient coping?*

There was a significant difference between groups (high, medium and low resilient coping; large effect size) for levels of *depression* as shown by a one-way ANOVA ($F_{(2,107)}=10.92$, $p<.001$, $\omega^2=0.15$). Post-hoc tests revealed significant differences in depression between low and high groups ($p<.001$, 95%CI: 2.65 to 9.20) and between low and medium groups ($p=.005$, 95%CI 1.02 to 7.13) but not between medium and high groups ($p=.451$, 95%CI -1.79 to 5.50).

There was a significant difference between groups (high, medium and low resilient coping; large effect size) for levels of *anxiety* ($F_{(2,107)}=6.89$, $p=.002$, $\omega^2=0.10$). Post-hoc tests showed significant differences in anxiety reported between the low and high resilient coping groups ($p=.006$, 95%CI 0.77 to 5.60) and between the low and medium resilient coping groups ($p=.011$, 95%CI 0.53 to 5.02), but not between medium and high resilient coping groups, ($p=.930$, 95%CI -2.28 to 3.09).

There was a statistically significant difference, with a large effect size, between groups for levels of *stress* ($F_{(2,107)}=12.16$, $p<0.001$, $\omega^2=0.17$). Post-hoc tests revealed a significant difference in the stress reported between low and high resilient coping groups ($p<.001$, 95%CI 2.97 to 8.77) and between low and medium resilient coping groups ($p=.023$, 95%CI 0.35 to 5.76), but not medium and high resilient coping groups ($p=.100$, 95%CI -0.41 to 6.04).

There was a significant difference between groups (high, medium and low resilient coping; large effect size) for levels of *burden* ($F_{(2,107)}=12.43$, $p<.001$, $\omega^2=.17$). Post-hoc tests revealed a significant difference between low and high resilient coping ($p<.001$, 95%CI 5.51 to 16.45) and between low and medium ($p=.010$, 95%CI1.23 to 11.33) but not between medium and high resilient coping groups ($p=.162$, 95%CI -1.37 to 10.72).

Figure 6-2 shows the comparisons of carers with low, medium, and high resilient coping for each variable (depression, anxiety, stress and burden).

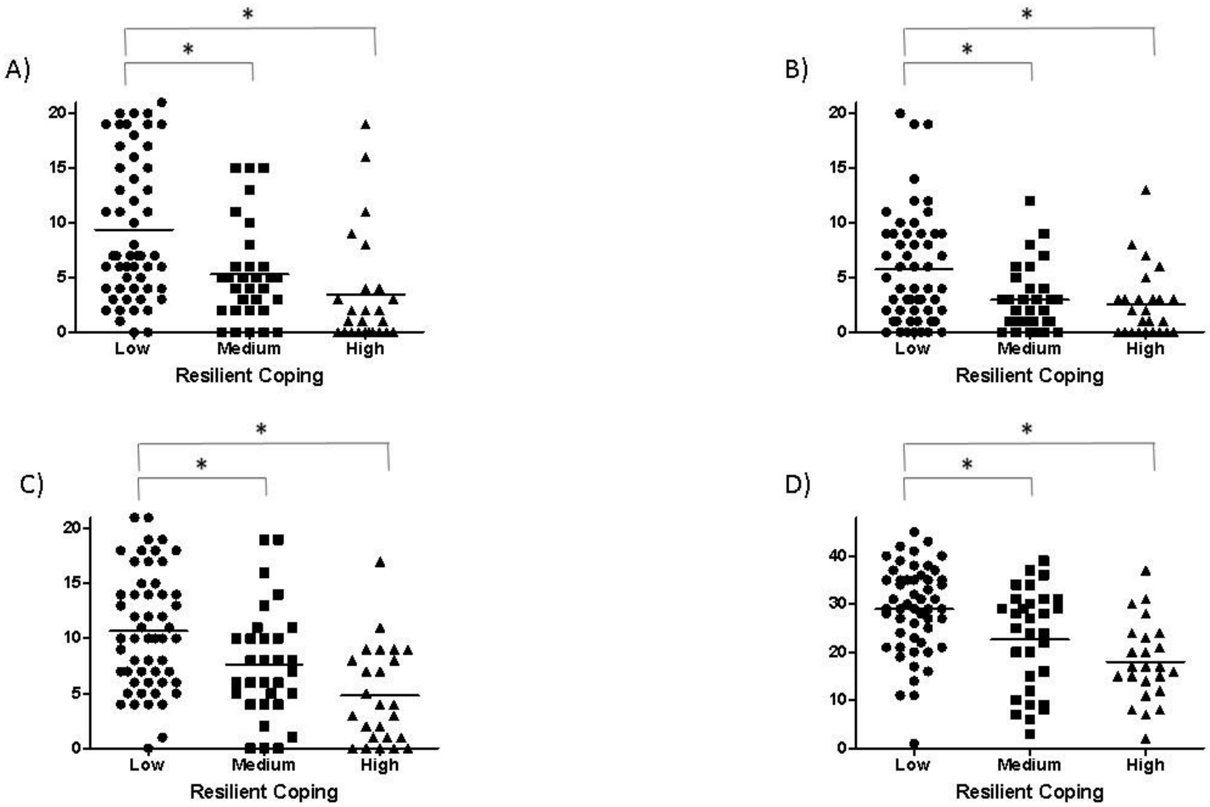


**Figure 6-2** Comparisons of carers with low, medium and high resilient coping for depression, anxiety, stress and burden

—— Indicates mean score, * between-group differences p≤.05

*Does resilient coping act as a mediator between distress and wellbeing?*

Mediation analyses were conducted for the four distress variables (Figure 6-3).

There was a significant direct effect between depression and carer wellbeing, showing a negative relationship between these variables (*b*= -1.65; *p*<.01). When resilient coping was included as a mediator in the model, there was a significant indirect effect (*b*= -0.76, 95% BCa CI -1.11 to -0.35), showing that resilient coping mediated the relationship between depression and wellbeing with a medium to large effect size (completely standardised indirect effect = -0.22).

Resilient coping as a mediator in the anxiety-wellbeing relationship:

There was a significant direct effect between anxiety and wellbeing (b= -1.92, *p*<.01), showing a negative relationship between these variables. When resilient coping is included as a mediator there is a significant indirect effect (b= -1.04, 95% BCa CI -1.49 to -0.60), showing that resilient coping mediated the relationship between anxiety and wellbeing with a medium to large effect size (completely standardised indirect effect = -0.22).

Resilient coping as a mediator in the stress-wellbeing relationship:

There is a significant direct effect of stress on wellbeing, showing a negative relationship (*b*= -1.52, *p*<.01) and when resilient coping is added as a mediator there is a significant indirect effect (*b*= -0.96, 95% BCa CI -1.40 to -0.56), showing that resilient coping mediated the relationship between stress and wellbeing with a medium to large effect size (completely standardised indirect effect = -0.20).

Resilient coping as a mediator in the burden-wellbeing relationship:

There was also a significant direct effect between burden and carer wellbeing (*b*=-0.96, *p*<.01), showing a negative relationship between these variables. There is a significant indirect effect when resilient coping is included as a mediator (*b*= -0.42 95% BCa CI -0.64 to -0.22), showing that resilient coping mediated the relationship between burden and wellbeing with a small effect size (completely standardised indirect effect = -0.02).

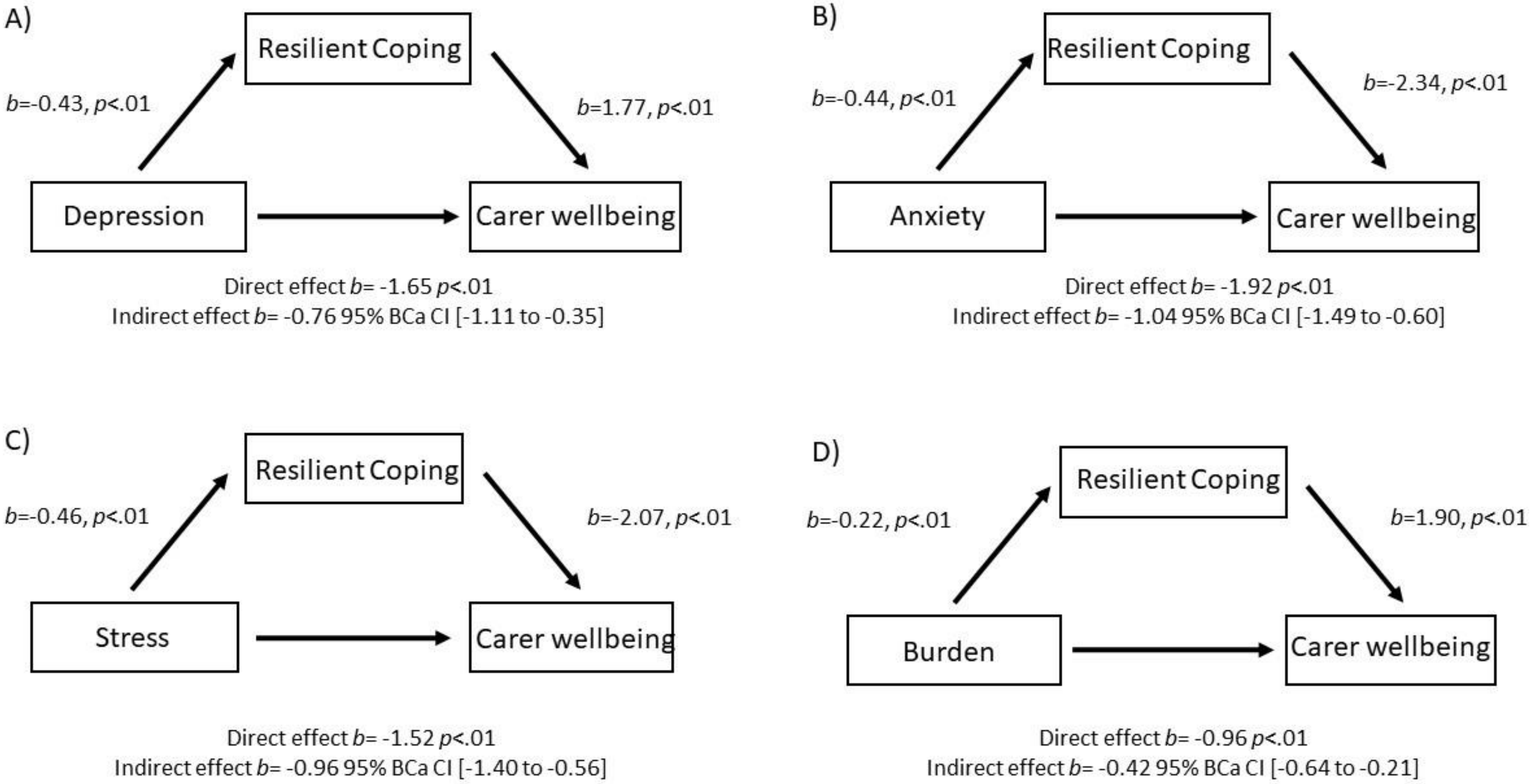


**Figure 6-3** Four separate mediation analyses testing whether resilient coping mediates the relationship between carer wellbeing and carer distress variables. A) depression B) anxiety C) stress and D) burden

## 6.5 Discussion

The analysis aimed to investigate the role of resilient coping in supporting carer wellbeing. The findings support the first hypothesis that highly resilient carers report less distress than carers with lower resilience. Low resilient carers had significantly higher depression, anxiety, stress, and burden scores than high or medium resilient carers. In accordance with the second hypothesis, the results showed that resilient coping is likely to mediate the adverse relationship between psychological distress and subjective wellbeing for carers of people with dementia. This suggests that resilient coping may have a strong effect on wellbeing as it is a multi-dimensional concept, involving beliefs and behaviours that also promote subjective wellbeing (Windle et al. 2008).

These findings are consistent with previous research on carer distress, which showed that higher levels of depression, anxiety and stress were associated with higher burden (Wong et al. 2019). This analysis builds upon these earlier findings by demonstrating that carers with high resilient coping have lower distress scores across all measures. This aligns with findings that resilience can improve wellbeing in other groups such as formal carers (Shahdadi et al. 2017; Mealer et al. 2012). However, in addition this analysis showed that informal carers who report high resilient coping can concomitantly experience symptoms of distress, especially in relation to feelings of burden – resilience and distress can co-exist. This ‘resilience-paradox’ has been noted in other studies (Wilks and Croom, 2008; Southwick et al. 2014) and needs further investigation.

The findings showed that resilient coping mediated the relationship between depression, anxiety, stress and burden and carer subjective wellbeing. However, despite the medium to large effect sizes found, it is also important to note that resilient coping only partially mediated the relationships between psychological distress and subjective wellbeing. This suggests that there are factors other than resilient coping that ameliorate or exacerbate distress in carers. Factors that have been investigated previously include optimism (Ruisoto et al. 2018) and psychosocial characteristics as predictors of distress related to behavioural and psychological symptoms (Feast et al. 2017).

The mediation effects of resilient coping were similar across models for depression, anxiety and stress, which indicates that improving resilience may be useful alongside other interventions specifically targeting these symptoms. Cognitive-based therapies (e.g. CBT) seem to be effective in reducing carer anxiety and depression (Kishita et al. 2018). When this is considered alongside the positive results from resilience training in other population groups (e.g. healthcare employees, parents (Kaboudi et al. 2018; Werneburg et al. 2018)), it seems that a potential combination of CBT-based approaches and resilience training such as SMART (Sood et al. 2014, Chesak et al. 2015) may be a beneficial and cost-effective mechanism to support carers.

High, medium, and low resilient carers did not differ in socio-demographic characteristics, except for gender. In this analysis, female carers reported higher resilient coping, but this may be a reflection of the fact that the number of male participants was smaller. Interestingly, these findings stand in contrast to the normative data for the assessment of resilience (BRCS), which suggests that men, overall, have higher resilient coping than women (Kocalevent et al. 2017). However, female carers are considered to be at greater risk of pathology associated with depression, anxiety, stress and burden than male carers (Erol et al. 2015). Providing care may itself lead to women having unexpected opportunities to develop resilience. The small sample size and bias towards female participants in this analysis are limitations and the findings related to gender should be interpreted with caution.

Limitations should be noted. The sample was recruited via self-referral from community organisations and via online forums, and for this reason, the sample may present a skewed view of carers, as the participants all self-identified as carers and were engaged with some form of carers' support services. As a consequence, this may have resulted in the sample being biased towards less distressed carers, who may be more willing and able to take part in this type of research. The use of self-report survey questionnaires may present a limitation as carers' responses may have been influenced by social desirability or inaccurate recollection. Future studies may benefit from the use of more objective measures of the factors under investigation. Also, future research should investigate the influences of resilient coping on broader outcomes for both the carer and the person with dementia.

## 6.6 Summary

This chapter has examined one of the factors at the individual level of the resilience framework, namely carers' psychological resources. The findings have identified that psychological distress is not an inevitable consequence of caring, and that resilient coping is just as likely a response, if not a more frequent one, to adverse life events than severe psychological distress (Bonanno, 2004). This has implications for nurses and allied health professionals working with carers of people with dementia and other neurological conditions. As a preventative measure to reduce morbidity associated with distress, practitioners may offer care and support that promotes or maintains resilience. Strategies that assist carers to develop the skills and attributes associated with resilient coping, namely problem solving, managing emotions, and replacing losses (for example in a support network), may have particular benefits in promoting wellbeing and improving long-term outcomes.

The next chapter moves on from the individual-level resources of the framework and examines social support settings as a resource for resilience from the community level.

# 7 SOCIAL SUPPORT SETTINGS AND RESILIENCE

## 7.1 Foreword

The previous analyses examined carers' individual psychological resources and their relationships with resilient coping and wellbeing. This chapter presents the aims, methods, results and discussion of the analyses that examined the relationships between attendance at a social support setting and resilience, subjective wellbeing and social support. The findings reported in this chapter have been published in the Journal of Alzheimer's Disease (Jones et al. 2018). The hypothesis that attendance at a Dementia Café had a positive relationship with resilience, wellbeing and social support was tested and additional analyses were conducted to examine the socio-demographic characteristics of café attendees and non-attendees. This information was fed back to local stakeholders as part of a wider evaluation of the Dementia Café model in Norfolk.

## 7.2 Hypotheses

The analyses test the following hypotheses:

1) Café attendees will have greater resilience, subjective wellbeing and perceived social support than non-attendees.
2) Specific socio-demographic characteristics will predict café attendance.

## 7.3 Methods

*Design*

This was a cross-sectional analysis comparing dementia carers who attended a Dementia Café with a sample of carers who were non-attendees. Data were collected through self-completed postal surveys.

*Participants*

Inclusion criteria:

1) Participants to be aged over 18 years

2) Providing care and/or support to a friend or relative with dementia
3) Willing and able to complete a survey in English

Exclusion criteria:

1) Paid carers and volunteer befrienders were excluded

The target recruitment figure was based on data provided by the Alzheimer's Society regarding the number of people attending Dementia Cafés in Norfolk. They estimated this number to be 250 people; this figure included people with dementia, paid carers, carers who attended after the person with dementia had died and young carers (under 18 years). Therefore, it was estimated that approximately 100 carers were eligible to participate, and it was predicted that half of this figure might take part in the study, so a target figure of 50 attendees and 50 non-attendees was set.

*Procedure*

As described in Chapter 3, there were three routes to recruitment, shown in Figures 3.2 and 3.3. Information about the research was published through presentations or distribution of participant information leaflets (Appendix 12.4) at Dementia Cafés and health and wellbeing events facilitated by either HealthWatch or the Alzheimer's Society UK.

*Setting*

The research was conducted in Norfolk, UK. This English county has a population of 892,900, 213,000 of whom are aged over 65 years. It is a largely rural county with a population density of 166 people per km$^2$. There are approximately 16,400 people living with dementia in Norfolk (Norfolk Insight, 2017). The first Dementia Café opened nine years ago, and a network of cafés grew across the county located in care homes, hospitals, and local community settings. The origins and role of Dementia Cafés are described in Chapter 2. The limitations of recruiting participants at the Dementia Cafés are discussed in Chapter 10.

There is no overarching model or philosophy for Dementia Cafés in the county. Services vary in frequency of meeting and types of activity offered, but the basic principles are retained, i.e. meetings are for people living with dementia and their carers and 'are held in a friendly, social, café-like atmosphere, where people can converse, listen to themed talks or interviews, enjoy refreshments and music and come and go freely' (Jones and Miesen, 2011).

Cafés were included if they were open access, i.e. there were no referral criteria, were open to all carers and people with dementia, met at least monthly in a community setting and there were no membership costs. Cafés were excluded if they were facilitated by clinicians and located within a healthcare setting, i.e. in the district general hospital or mental health unit or where attendees required a formal referral from a healthcare professional. The aim of this research was to focus on community settings which the person with dementia and their carer could attend together for social support. There were 22 Dementia Cafés across the county at the beginning of the project. This number decreased during the research as cafés closed or merged due to financial pressures. Seventeen Dementia Cafés were approached and recruited from in total.

### *Questionnaires*

### *Café attendance and demographic variables*

Attendance at a Dementia Café was assessed by asking participants to indicate whether they had attended a café within the previous month, how frequently they had attended, and whether they had attended with or without the person with dementia.

Demographic variables included carer gender, age group, employment, relationship status and education. Spouses caring for a relative with dementia were compared with non-spouse carers as this caring dyad is identified as distinct from other caring relationships (O'Rourke et al. 2010). Education categories were defined by the years of formal schooling. Questions about the person with dementia and the context of care included: number of hours caring per week, type of dementia and whether or not the carer resided with the person with dementia.

### *Questionnaires*

Psychosocial variables (resilience, wellbeing and social support) were assessed using the BRCS (Sinclair and Wallston, 2004), the Personal Wellbeing Index-Adult (PWI-A) (International Wellbeing Group, 2006) and the Medical Outcomes Study – Social Support Survey (MOS-SSS) (Sherbourne and Stewart, 1991). Details of these questionnaires are given in Table 3-2.

**3-2**

### Data analyses

To describe the psychosocial characteristics and demographic profiles of café attendees and non-attendees, means, standard deviations, and percentages were calculated. Kolmogorov-Smirnoff tests were used to assess the normal distribution of the psychosocial outcome measures of resilience (BRCS), subjective wellbeing (PWI-A) and social support (MOS-SSS). Categorical differences in the demographic profiles of the attendee group and the non-attendee group were estimated using Chi-square tests. Categories where there were significant differences between the two sample groups (attendees and non-attendees) were retained for further analyses (i.e. gender and the number of years the carer spent in formal education). Independent t-tests were used to evaluate the differences between resilience, subjective wellbeing, and social support between the two sample groups (café attendees and non-attendees). Effect sizes for each of the outcome variables (resilience, social support and subjective wellbeing) on café attendance were calculated using Cohen's d. Logistic regression analyses were performed to evaluate the odds ratio of each predictor (resilience, social support, subjective wellbeing and the retained demographic variables mentioned above), with either café attendance or non-attendance.

However, before conducting the regression analyses, Spearman rank correlation analyses were performed to exclude potential multicollinearity among variables. Any variables with correlations greater than 0.70 were considered for removal. This threshold effectively indicated the point at which model estimation and subsequent prediction could be severely distorted by multicollinearity (Dormann et al. 2013). None of the variables suggested multicollinearity, so all were retained for entry into the regression analysis.

Logistic regressions were run in two stages. Stage one examined each predictive variable entered on its own (Models A-E, Table 7-2). In stage two all psychosocial variables (resilience, subjective wellbeing and social support) and the socio-demographic characteristics deemed significant were inputted into a multivariate direct entry logistic regression analysis to examine predictor variables and the outcome (Dementia Café attendance), with all other covariates held constant (Table 7-3). The software package IBM SPSS statistics v23.0 was used, and statistical significance was set at $p< 0.05$.

## 7.4 Results

The socio-demographic characteristics of the participants, the number of hours care they provide and the type of dementia of the person they care for are shown in Table 7-1.

| | | Does not attend a Dementia Café (n=26) | Attends a Dementia Café (n=54) |
|---|---|---|---|
| **Gender (n=80)** | Male | 11 (42%) | 10 (19%) |
| | Female | 15 (58%) | 44 (80%) |
| **Age group, years (n=80)** | 30–49 | 0 | 2 (4%) |
| | 50–69 | 7 (27%) | 15 (28%) |
| | 70–79 | 12 (46%) | 21 (39%) |
| | 80+ | 7 (27%) | 16 (30%) |
| **Spousal carers (n=80)** | Spouse | 16 (61%) | 36 (67%) |
| | Other | 10 (39%) | 18 (33%) |
| **Years in formal education (n=78)** | Up to 12 years | 7 (27%) | 32 (59%) |
| | Up to 14 years | 11 (42%) | 12(22%) |
| | 17 years+ | 8 (31%) | 8 (15%) |
| **Employment status (n=80)** | Working (FT/PT) | 7 (27%) | 6 (11%) |
| | Retired/not working | 19 (73%) | 48 (89%) |
| **Care hours provided per week (n=80)** | 1–20 hrs | 3 (11%) | 9 (17%) |
| | 21- 40 hrs | 1 (4%) | 6 (11%) |
| | 41- 80 hrs | 22 (85%) | 39 (72%) |
| **Carer lives with PWD (n=80)** | Yes | 22 (85%) | 39 (76%) |
| | No | 4 (15%) | 15 (24%) |
| **Type of dementia (n=68)** | Alzheimer's disease | 7 (27%) | 19 (35%) |
| | Vascular dementia | 5 (19%) | 7 (13%) |
| | Mixed (Alzheimer's and Vascular) | 9 (35%) | 11 (20%) |
| | Lewy body disease/FTD | 2 (7.7%) | 2 (4%) |
| | Other | 0 | 6 (11%) |

FT = full time; PT = Part time; PWD = Person with dementia; FTD = Fronto-temporal dementia. % rounded to whole number.

**Table 7-1** Socio-demographic characteristics of participants

### *Who attends Dementia Cafés?*

To fully understand the characteristics of those attending Dementia Cafés, I compared carers attending and not attending cafés. Attendees were more likely to be female ($\chi^2$ (1, n=80)=5.13, p=.024), and café attendees also had fewer years of formal education ($\chi^2$ (3, n=78)=9.82, p=.020) than carers who did not attend.

Attendee and non-attendee groups were well matched for carer age group ($\chi^2$ (1,n=80)=0.174, p=0.68), employment ($\chi^2$ (1,n=80)=3.22, p=.073), spousal relationship to the person with dementia ($\chi^2$ (,n=80)=0.20, p=.65), hours per week spent caring ($\chi^2$ (1,n=80)=0.22, p=.27), and carer living with person with dementia ($\chi^2$ (1,n=80)=1.49 p=.22). The sample size was insufficient to make comparisons between different types of dementia.

As shown in Figure 7-1, café attendees reported higher resilience (mean difference -3.54, 95% CI -5.34 to -1.73; p<.001) and subjective wellbeing (mean difference -1.98, 95% CI -2.93 to -1.02; p<.001) than non-attendees. There was no significant difference in social support between the two carer groups (mean difference -0.42, 95% CI -0.92 to 0.08; p=.12).

Resilience and subjective wellbeing showed a large effect size: d= 0.89 and d=0.94, respectively. Social support had a medium effect size: d=0.41.

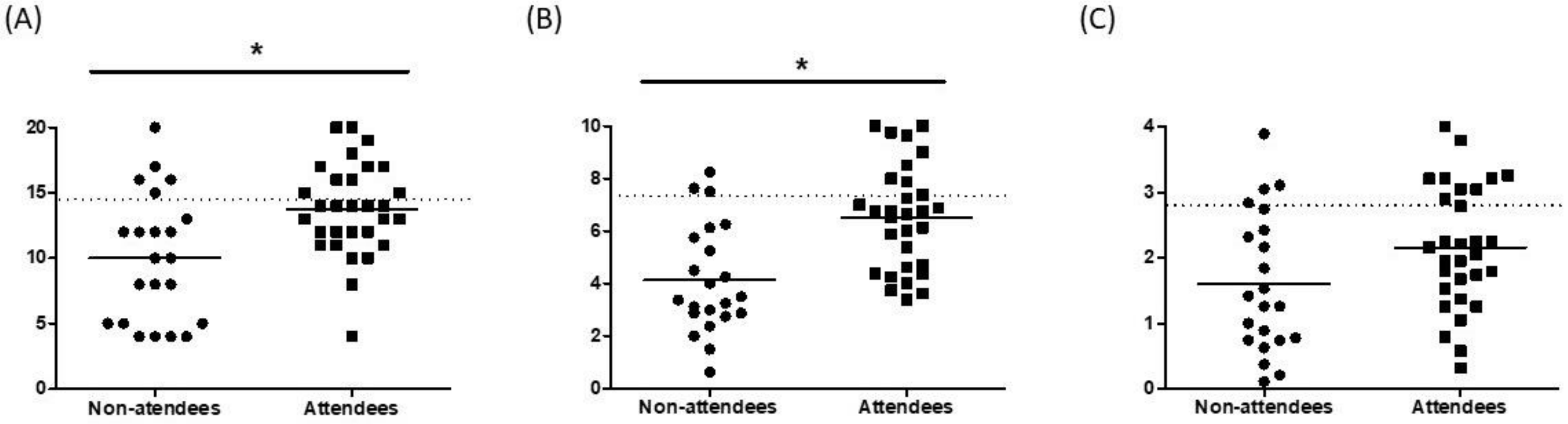


**Figure 7-1** Comparisons of café attendees and non-attendees for (A) resilience (B) subjective wellbeing and (C) social support

---------Indicates sample mean, ……….. Indicates the normative mean value for each scale. Café attendees score significantly higher than non-attendees for resilience and subjective wellbeing (*p<.001)

*What predicts café attendance*?

Given that all effect sizes from the previous analysis were above 0.4, to understand which psychosocial characteristics may predict café attendance, the variables of interest (Table 7-2) were inputted into five bivariate analyses.

With café attendance as the dependent variable, independent regression analyses showed that café attendance was 1.63 times more likely to occur in those with higher subjective wellbeing, and 1.26 times more likely to occur in those with higher resilience. Café attendance did not seem to be affected by social support. Café attendees were 3 times more likely to be female and less likely to have over 13 years' formal education.

| **Predictor variables at each separate univariate analyses** | **OR** | **(95%CI)** | ***p* value** |
|---|---|---|---|
| *Model A:* Subjective wellbeing | 1.63 | (1.24-2.14) | ***p*=.001** |
| *Model B:* Resilience | 1.26 | (1.10-1.45) | ***p*=.001** |
| *Model C:* Perceived social support | 1.47 | (0.93-2.32) | *p*=.104 |
| *Model D*: Gender | | | |
| Male vs Female | 3.227 | (1.14-9.10) | ***p*=.03** |
| *Model E:* Years in formal education | | | |
| Up to 12 | 4.58 | (1.28-16.38) | ***p*=.02** |
| Up to 14 | 1.10 | (0.30-3.91) | *p*=.89 |
| 17+ | 0 | | |

0 indicates reference category. Significant *p*-values (*p*<.05) are marked in bold

**Table 7-2** Logistic regression models with attendance at a Dementia Café as the dependent variable.

Next, to investigate the association of the variables with other factors held constant, a multivariate analysis was run, with café attendance as the dependent variable, and subjective wellbeing, resilience, social support, gender and years in formal education as covariates (Table 7-3).

In this final model, having higher subjective wellbeing increased the odds of attending a café by 1.63 times. When all covariates are controlled for, the effect of being female and reporting high resilience no longer affected attendance at a Dementia Café. However, a significant association with the number of years of formal education remained, where fewer years of formal education had a positive effect on café attendance.

| **Predictor variables** | **Model B**<br>**(Adjusted predictive variables)**<br>**OR** | **(95%CI)** | ***p*** |
|---|---|---|---|
| Subjective wellbeing | 1.63 | (1.10-2.42) | ***p*=.02** |
| Resilience | 1.13 | (0.933-1.35) | *p*=.22 |
| Perceived social support | 0.59 | (0.29-1.22) | *p*=.15 |
| Gender | | | |
| Male vs Female | 3.11 | (0.86-11.3) | *p*=.09 |
| Years in formal education | | | |
| Up to 12 | 4.90 | (1.12-21.36) | ***p*= .03** |
| Up to 14 | 0.96 | (0.21-4.395) | p=.96 |
| 17+ | 0 | | |

0 indicates reference category; significant *p-values (p*<.05*)* are marked in bold

**Table 7-3** Multivariate logistic regression analyses with attendance at a Dementia Café as the dependent variable

## 7.5 Discussion

The analyses reported within this chapter aimed to investigate the demographic and psychosocial characteristics of carers who attend Dementia Cafés, and to identify which of those factors may influence the likelihood of carers attending such cafés. The findings only partially uphold the first hypothesis that café attendees will have greater resilience, subjective wellbeing, and perceived social support than non-attendees. The findings of this analysis show that carers attending Dementia Cafés have greater resilience and report higher subjective wellbeing, but do not report differences in social support when compared to their non-attending peers.  In response to the second hypothesis that specific socio-demographic characteristics will predict café attendance, the results show that carers who had 12 years or less formal education were more likely to attend a café than carers with more years in education.

*Resilience*

To the best of my knowledge, this is the first research to examine resilience in carers attending Dementia Cafés. The findings demonstrate that carers attending cafés have higher resilience. Even though this analysis is unable to establish cause or effect, the large effect size found confirms that attendance at peer support groups can play an important role in the resilience process, as found in other patient groups (Sadler et al. 2017; Stokar et al. 2014). Either cafés provide a range of opportunities that foster resilience, including providing information and contact with people who have similar experiences (Deist and Greeff, 2017; Donnellan et al. 2016), or those carers with greater resilience are most willing and able to attend cafés.

*Wellbeing*

Carers within the café attendee group report greater subjective wellbeing. This analysis focuses on community-run cafés but supports previous findings from cafés facilitated by healthcare professionals within a hospital setting (Merlo et al. 2018). The higher subjective wellbeing described by café attendees may occur because carers and people with dementia benefit from attendance at support groups by having opportunities to consider planning for their future security (Gaugler et al. 2011) and feeling part of the community (Mather, 2006). Dementia Cafés offer a supportive environment for both the person with dementia and their carer, and this form of mutual support has been found to promote the relationship between the person cared for, the carer and others (McFadden and Koll, 2014) while improving quality of life and subjective wellbeing (Wang et al. 2012).

### *Social support*

Attending cafés does not seem to increase one's sense of social support. This is rather surprising given that Dementia Cafés are designed to promote feelings of social inclusion, social wellbeing and supportive friendships (Dow et al. 2011), 2011), reduce social isolation (McFadden and Koll, 2014) and promote the development of new social networks (Greenwood et al. 2013). In the current work, none of these potential benefits seems to translate to feelings of increased support beyond the group. Research has identified that resilient carers were more likely to use group participation to gain informational support, but non-resilient carers went to groups for social interaction (Donnellan et al. 2016). The café setting potentially meets both these needs, but the benefits are not sustained when social support satisfaction is assessed as a whole. Inconsistent findings of the wider social support impact of café attendance beyond each group session may indicate a flaw in the café model. Alternatively, current research tools and methodologies may be insufficient to accurately measure the potential beneficial impact of cafés on social support.

### Socio-demographic characteristics

In contrast to studies that have examined other social support settings, this analysis found that carers with fewer years' formal education were more likely to attend than carers who had a college or university education. Attendees are significantly more likely to have finished their education aged 16 years or younger. Education level has been shown to be associated with attendance at support groups for other carer groups, but as far as I am aware this is the first time that it has been investigated in the Dementia Café setting. Studies of facilitated support groups in other populations have found that attendees were more likely to have a college education (Katz et al. 2002). In this research, all Dementia Cafés were open access with no referral criteria and people could attend as and when they wished. It may be that this less prescriptive approach is more appealing or accessible to people with fewer years of formal education than the support groups of other studies. Future studies should address this question in more detail.

The findings show that some carer groups are under-represented at cafés, i.e. male carers and carers aged less than 50 years old. There is still controversy in the literature over whether social support groups appeal more to women than men. This corroborates findings from other disease-specific support groups, including those in cancer care (Krizek et al. 1999) and multiple sclerosis (Peters et al. 2003). However, studies on dementia carers are inconsistent, as some studies show that gender is not a significant factor in attendance at such support groups (Grässel et al. 2010) while others demonstrate that male carers attend social support groups far less frequently than female carers. Male carers believe that support groups are tailored to women and have an “emotionally expressive climate” (Pretorius et al. 2009). It may be that the informal structure and focus on peer discussion at Dementia Cafés appeal more to women than men.

### Limitations

The small sample size is a limitation. A priori power calculations indicated that a sample of 80 carers in each group would have been ideal. Target recruitment figures were set on a pragmatic basis, taking into account the limitations of a postal survey and access to cafés and carers. Some of the findings related to the lack of statistical differences in the socio-demographic characteristics of café attendees and non-attendees should be considered with caution. Additionally, the recruitment procedures used may have created a selection bias. Recruitment favoured carers who were already engaged with Dementia Cafés. All cafés ran during normal working hours, which may have potentially excluded employed carers. It was not possible to differentiate cafés by type of community provider, given their small numbers. This is a limitation as there may have been considerable variation in the provision in terms of activities available, the number of people attending and the role (and expertise) of the facilitators in cafés run by large national charities or small local voluntary groups. Another potential limitation is that the original estimates of numbers of café attendees were different to the numbers identified during recruitment. Several carers attended more than one café and several cafés closed during the course of data collection, reducing the pool of eligible carers. Finally, the tool evaluating resilience has been used in a variety of populations, including adult carers of people with developmental disabilities, but this is the first sample of dementia carers.

### Next steps

Dementia Cafés may bring about benefits in the form of resilience, social support and wellbeing, but they are not being accessed by all groups of carers. Carer groups under-represented at cafés include male carers and younger carers aged less than 50 years old. If cafés are going to continue to grow and be the main post-diagnostic community support for families, it will be necessary to clarify the café model and improve accessibility to all carers. Exploring ways to improve the opportunities for carers to develop social support networks they perceive to be helpful beyond the café session is an important aspect of post-diagnostic support – one not yet supported through café attendance.

## 7.6 Summary

This chapter identified that the use of a social support setting was positively associated with higher resilience and subjective wellbeing in carers. However, there was no relationship between attendance at the social support setting and the level of social support that carers felt was available to them. There is evidence that social support is a key resource for resilience (Donnellan et al. 2016; Wilks et al. 2011) and the next analyses explore this in greater depth. Chapter 8 examines four specific types of social support and their relationship with resilient coping.

# 8 DOMAINS OF SOCIAL SUPPORT RESILIENCE

## 8.1 Foreword

Continuing on from the previous chapter looking at community-level factors in the resilience framework (Windle and Bennett, 2011), this chapter takes a closer look at the availability of different types of social support that carers feel they have available to them. It examines four types of social support (emotional/informational, tangible, affectionate support and positive social interaction) and examines their relationships with resilient coping. This chapter further develops the understanding of resilient coping and social support by testing the hypothesis that specific types of social support predict high resilient coping.

## 8.2 Hypotheses

The broad aims described in the abstract were refined into the following hypotheses:

1) Carers who report high resilient coping will have greater perceived social support.
2) Specific types of social support will have greater influence on resilient coping.

## 8.3 Methods

This is the third and final analysis of the quantitative data gathered via the postal survey, described in Chapter 3. It uses data gathered about carer socio-demographic variables, resilience and social support. The BRCS was used to measure resilience. The Medical Outcomes Study-social support survey was used to measure the availability of different types of social support that carers felt was available to them. Details of these measures are given in Table 3-2.

*Data analyses*

Descriptive statistics were used to report socio-demographic characteristics. Variables included carer age, gender, education, employment, residence (with or without the person with dementia) and relationship to the person with dementia.

Demographic differences between carers with *high* and *low* resilient coping were estimated using Chi-square tests.

Kolmogorov-Smirnoff tests and visual inspection of histograms were used to assess the normality of the resilience measure (BRCS) and subscales of the social support measure (MOS-SSS). Resilient coping was normally distributed. In order to compare groups, a dichotomised value for resilience was established using the mean score of the sample (BRCS total). Values equal to or below the mean score (≤13) were categorised into the *low* resilient coping group, and carers greater than the mean (≥14) were included in the *high* resilient coping group.

Means and standard deviations were calculated for each domain of social support for the group as a whole and for both the *low* and *high* resilient coping groups. Social support data were not normally distributed for any of the subscales. Therefore, the Mann-Whitney U test of significance was used for testing the hypothesis that carers with *low* and *high* resilient coping differed in their levels of perceived support. Effect sizes were calculated from the z scores of the Mann-Whitney U tests. Collinearity diagnostics showed all variance inflation factors (VIF) were <3 and tolerance was above 0.3.

The predictors of resilient coping were investigated using logistic regression modelling. First, considering resilient coping as the dependent variable (*high* vs *low* resilient coping), each predictive variable was entered on its own, i.e. each domain of social support and the socio-demographic variables (model A). Next, a multivariable logistic regression model (model B) was used, taking resilient coping as the dependent variable (*high* vs *low* resilient coping) and all the predictor variables were entered together to control for any confounding effects. All data analyses were computed in IBM SPSS Statistics v.25 and significance was set at $p \leq .05$.

## 8.4 Results

*Sample characteristics*

This sample comprises 108 carers (72%). An overview of the sample characteristics is given in Table 8-1. The majority of the sample were women (69%); 61% of carers were aged 70 years or above. Spousal relationship was most common (61%), as was carer co-residence with the person with dementia (78%). The characteristics of the respondents were comparable to those of dementia carers in the UK as a whole (Wimo et al. 2013).

| | | Low resilient coping (n=53) | High resilient coping (n=55) | Chi-Square tests |
|---|---|---|---|---|
| Gender | | | | $\chi^2_{(1, n=108)}$=8.09, *p=.004** |
| | Male | 23 (43%) | 10 (18%) | |
| | Female | 30 (57%) | 45 (82%) | |
| Age group (years) | | | | $\chi^2_{(2, n=108)}$=1.06, *p=.59* |
| | <70 | 19 (36%) | 23 (42%) | |
| | 70–79 | 19 (36%) | 21 (38%) | |
| | 80+ | 15 (28%) | 11 (20%) | |
| Formal education (years) | | | | $\chi^2_{(2,n=108)}$=0.14, *p*=.93 |
| | Up to 12 | 23 (43%) | 22 (40%) | |
| | Up to 14 | 15 (28%) | 17 (31%) | |
| | Up to 17+ | 15 (28%) | 16 (29%) | |
| Employment | | | | $\chi^2_{(1,n=108)}$=0.40, *p*=.53 |
| | FT/PT | 9 (17%) | 12 (22%) | |
| | Retired/Not working | 44 (83%) | 43 (78%) | |
| Spousal carers | | | | $\chi^2_{(1,n=108)}$=1.063, *p*=.30 |
| | Spouse | 35 (66%) | 31 (56%) | |
| | Other | 18 (34%) | 24 (43.6) | |
| Carer resides with the PWD | | | | $\chi^2_{(1,n=108)}$= 3.06, *p*=.08 |
| | Yes | 45 (85%) | 39 (71%) | |
| | No | 8 (15%) | 16 (29%) | |

PWD= person with dementia, FT=full-time, PT=part time, **p*<.05.

**Table 8-1** Socio-demographic characteristics of carers by high and low resilient coping.

As illustrated in Table 8-1, the sample of carers was split into two groups, *low* or *high* resilient coping based on BRCS scores. There were no significant differences between the groups for age ($\chi^2_{(2, n=108)}$=1.06, *p=.59*), education ($\chi^2_{(2,n=108)}$=0.14, *p*=.93), employment ($\chi^2_{(1,n=108)}$=0.40, *p*=.53), relationship to the person with dementia ($\chi^2_{(1,n=108)}$=1.063, *p*=.30) or residence with the person with dementia ($\chi^2_{(1,n=108)}$= *3.06*, *p*=.08). There was a significant difference between groups for gender, with more women reporting high resilient coping ($\chi^2_{(1, n=108)}$=8.09, *p*=.004).

*Perceived availability of social support*

When the sample was examined as a whole, only four (3.7%) carers said they 'always' had access to all domains of social support. Tangible support was perceived as the least available (mean=1.74, SD=1.37), as 23 (21.3%) participants scored zero for this domain, indicating they had no access to practical help from friends or family. Affectionate support was perceived as the most available (mean= 2.45, SD=1.34), as 30 (27.8%) participants reported that they always had access to this domain of social support.

*Are there differences in social support between carers with high and low resilient coping?*

When comparing carers with *high* and *low* resilient coping, those with low resilient coping consistently reported lower scores on all domains of social support, indicating they perceived that they had less access to social support, as shown in Figure 8-1.

Likewise, there was also a significant difference between *low* and *high* resilient coping groups for affection (mean rank difference 19.34, U=1016.50 z= -2.756, *p*=.006). There was a small effect size (r=0.27) of affection on resilient coping.

Finally, *low* resilient coping carers also perceived that they had less availability of positive social interaction than carers who had *high* resilient coping scores (mean rank difference= 18.89, U=947.5, z= -3.175, *p*=.001) and the effect size of positive social interaction on resilient coping was small (r=0.30).

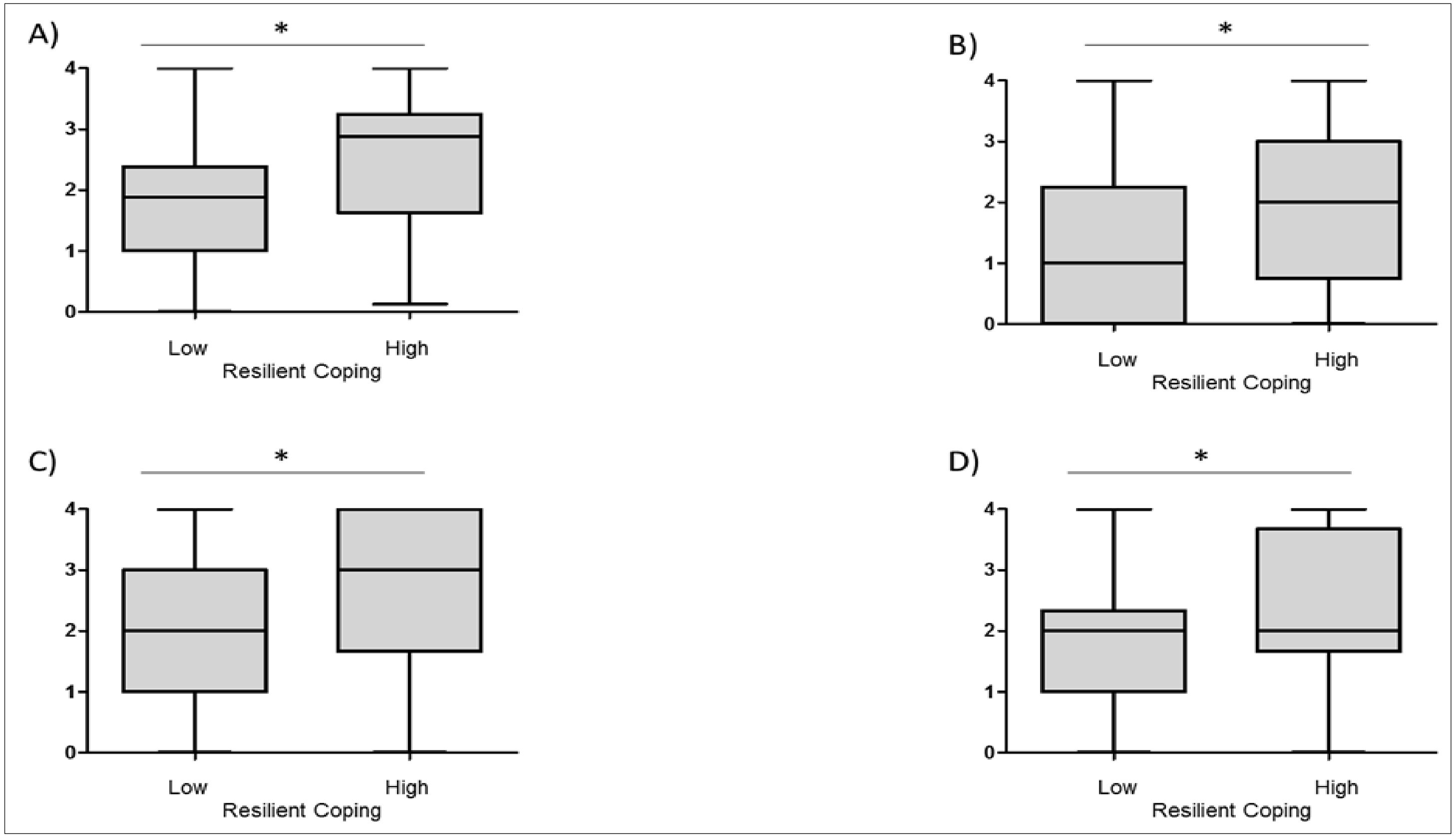


**Figure 8-1** Comparisons of carers with high and low resilient coping for domains of social support

A) emotional/informational support, B) tangible support, C) affection and D) social interaction. $^*p<.05$

*Low* resilient carers reported significantly less availability of emotional/informational support than *high* resilient carers (mean rank difference=20.17, U=913.00, z= -3.35, *p*=.001). However, while the difference between carer groups was significant, the effect size of emotional/informational support on resilience was small (r=0.32).

The perceived availability of tangible support was also significantly lower for carers who reported *low* resilient coping (mean rank difference 14.77, U=1059.00, z= -2.47, *p*=.014) but the effect size of perceived availability of tangible support on resilient coping was again small (r=0.24).

*Can social support predict resilient coping?*

Each domain of social support significantly predicted *high* resilient coping*,* as shown in Model A, Table 8-2. Emotional/informational support had the greatest influence on *high* resilient coping (OR=1.92, 95%CI=1.29 to 2.88, *p*=.001). Carers with greater access to tangible support were also more likely to be *high* resilient copers (OR=1.43, 95%CI=1.07 to 1.91, *p*=.017). Equally, greater availability of affectionate support (OR=1.49, 95%CI 1.10 to 2.00, *p*=.010) and positive social interaction (OR=1.76, 95%CI=1.24 to 2.49, *p*=.002) predicted *high* resilient coping.

| | | **MODEL A** | **MODEL B** |
|---|---|---|---|
| **Variables** | | **Each predictive variable on its own** | **All predictive variables entered simultaneously** |
| | | **OR (95%CI), *p value*** | **OR (95%CI), *p value*** |
| **Emotional/informational support** | | 1.92 (1.28-2.88), *p*=.01* | 1.56 (0.81-3.03), *p*=.19 |
| **Tangible support** | | 1.43 (1.07-1.91), *p*=.01* | 1.04 (0.65-1.67), *p*=.86 |
| **Affection** | | 1.49 (1.10-2.01), *p*=0.01* | 1.00 (0.59-1.70), *p*=.99 |
| **Positive social interaction** | | 1.76 (1.24-2.49), *p*=.01* | 1.30 (0.68-2.46), *p*=.43 |
| **Gender** | Male vs Female | 3.45 (1.44-8.27), *p*=.01* | 3.77 (1.33-10.67), *p*=.01* |
| **Age** | <70 years | 0 | 0 |
| | 70-79 years | 0.91 (0.38–2.18), *p*=.84 | 2.31 (0.66-8.10), *p*=.19 |
| | 80+ years | 0.61 (0.23-1.63), *p*=.32 | 1.48 (0.35-6.29), *p*=.59 |
| **Education** | up to 12 years | 0 | 0 |
| | up to 14 years | 1.19 (0.48-2.93), *p*=.71 | 1.64(0.56-4.81),*p*=.37 |
| | up to 17+ years | 1.12 (0.45-2.79), *p*=.82 | 1.62 (0.46-5.63), *p*=.46 |
| **Employment** | | | |
| | **FT/PT vs Retired/Not working** | 0.73 (0.28-1.92), *p*=.73 | 0.86(0.22-3.40), *p*=.83 |
| **Relationship** | Spouse vs Other | 1.51 (0.69-3.28), *p*=.30 | 0.93 (0.28–3.14), *p*=.91 |
| **Carer resides with PWD** | | | |
| | **Yes vs No** | 2.30 (0.90-5.60), p=.09 | 3.58 (1.00-12.88), p=.05 |

0= reference category, FT=full-time, PT= part time, PWD= person with dementia, **p*<.05

**Table 8-2** Logistic regression model with high resilient coping as the dependent variable

Model B, Table 8-2, reports the association between all social support and social demographic variables on resilience when adjusting for all other variables. While the model as a whole was significant ($\chi^2$ = 24.80, *p*=.016), no domain of social support individually predicted *high* resilient coping. Gender continued to be significant, with females being 3.77 times more likely to be *high* resilient copers (OR=3.77, 95%CI=1.33 to 10.6, *p*=.012).

## 8.5 Discussion

These analyses aimed to 1) compare the availability of perceived social support to carers with low and high resilient coping, and 2) identify whether any of the four domains of social support (emotional/informational support, tangible support, affection, and positive social interaction) predicted high resilient coping in carers. The findings of this analysis support the first hypothesis that carers with high resilient coping have greater perceived social support than carers with low resilient coping. However, the second hypothesis was not supported. None of the types of social support investigated predicted high resilient coping when other factors were controlled for. In addition, the results show that some carers feel that they have no access to any social support, particularly in relation to tangible support to assist them in a crisis.

*Tangible support*

In this practical context, tangible support includes functions such as someone being available to ‘help you if you were confined to bed,’ and ‘help with daily chores if you were sick’ (Sherbourne and Stewart, 1991). This lack of practical support is commonplace for carers generally (Carers UK, 2014a). It has implications for both the carer and the person with dementia, as both parties would be reliant on statutory services should the carer be unable to carry out the practical activities of daily living due to illness or injury. A lack of practical support has also been associated with greater carer morbidity as individuals are not able to take a break or attend to their own health needs (Carers UK, 2014a), whereas the availability of tangible support has a positive influence on life satisfaction (Morlett-Paredes et al. 2014).

*Positive social interaction*

After tangible support, positive social interaction was the form of social support carers perceived to be the least available. Carers of people with dementia are at greater risk of social isolation and declining social networks (Clay et al. 2008; Han et al. 2014). People with *high* resilient coping are more able to ‘replace losses encountered in life’ (Sinclair and Wallston, 2004) and this may enable them to develop new social support ties through dementia-related settings such as Dementia Cafés, support groups and online forums. Commonality and shared experience in caring have been suggested to foster resilience (Donnellan et al. 2016) and these settings may provide such opportunities.

### *Affectionate support*

Affectionate support was perceived as the most available form of support for both *high* and *low* resilient carers. This sample was biased towards spousal carers and although they may have derived support from a range of sources, including adult children and siblings, this finding may reflect the fact that resilient spousal carers are able to maintain affection in their marital relationship. Positive relationships between the carer and the person with dementia have been identified as important for resilience (Deist and Greeff, 2017). When describing aspects of resilience, carers rated ‘spending time together in an enjoyable way’ as a high priority (Joling et al. 2017). Carer resilience is also associated with a lower incidence of abusive behaviour on the part of the carer towards the person with dementia (Serra et al. 2018). Where a carer considers the person with dementia to be their main support, as in a mutual caring relationship, this is likely to change over time as the person with dementia becomes more dependent.

### *Emotional/informational support*

The results showed that *low* resilient carers reported significantly less availability of social support across all domains, including emotional/informational support. In the UK, the Care Act (HM Government, 2014) places a duty on statutory services to provide advice and information to carers, so it is unexpected that some participants reported no access to this domain. For the low resilient carers who reported no access to emotional/informational support, it may be argued that, although this support is available, it may be insufficient, not in a format accessible to the carer, not available at the right time, or not addressing their specific concerns (Georges et al. 2008; Robinson et al. 2009).

### *Socio-demographic characteristics*

The results identified that gender predicted *high* resilient coping, suggesting that socio-demographic characteristics may have a greater influence on resilient coping than wider social support from friends, family or neighbours. The finding that women were more resilient than men contrasts with the normative data for the BRCS, which suggests that overall, men have higher resilient coping scores than women (Kocalevent et al. 2017), although the difference is small. However, the majority of dementia carers are women (Georges et al. 2008) and this is reflected in the recruitment to this research; there were significantly more female participants, so this finding should be interpreted with caution.

### *Limitations*

There are additional limitations in this study. The social support questionnaire used did not measure the support asked for or received. It may be the case that *low* resilient carers did not feel able to ask for help so perceived that this help was unavailable. This analysis did not measure the number of people in each carer's social network, so social support may have come from a single relationship or a wider field of friends and family. Therefore, some carers who have reported that they 'always' had access to social support may, in fact, have a rather fragile support system, reliant on the availability of one friend or family member. As this was a cross-sectional analysis, it is not possible to confer cause and effect; therefore it is not possible to say whether high resilient coping promotes greater access to social support or whether social support boosts carers' resilient coping skills. Further details of the overall limitations of the methods chosen are given in section 10.5.

### *Conclusion*

The results show that when each domain of social support (emotional/informational support, tangible support, affection or positive social interaction) is considered individually, each of them has a positive relationship with *high* resilient coping. The results demonstrated that carers with *high* resilient coping skills perceived that they had greater access to all forms of social support than those with *low* resilient coping. However, no one domain of social support predicts *high* resilient coping. Health and social care providers should enable carers to maintain existing and develop new social support networks, to ensure that they have access to all the domains of social support required to support their resilience.

## 8.6 Summary

This chapter is the third analysis of the quantitative survey data. Previous chapters have explored subjective wellbeing and the use of community social support settings. This analysis contributed to the understanding of the perceived availability of social support to carers. The next chapter uses qualitative methods to explore how carers employ these resources and develop resilient coping strategies.

# 9 WHAT RESILIENT COPING STRATEGIES DO INFORMAL CARERS USE TO OVERCOME CARING CHALLENGES?

## 9.1 Foreword

Chapter 5 described the first qualitative analysis identifying carers' conceptualisations of resilience, and Chapters 6, 7 and 8 then explored the role of resilient coping and its relationships with social support and carer wellbeing. This chapter presents a further analysis of the interview data gathered for Chapter 5 and builds on the quantitative findings to highlight examples of the resilient coping strategies that carers with both high and low resilience use.

Three themes describing resilient coping strategies in response to caring challenges were identified: 1) *independence,* 2) *integration* and 3) *faith and fellowship*. Carers with high resilient coping were able to successfully maintain a strong sense of identity, integrating the role of carer into their own sense of self. Low resilient carers used strategies that sacrificed their previous identity to the role of dementia carer or caused them to compartmentalise their lives. Carers with high or low resilience used personal faith and wider religious fellowship as a resilient coping strategy. The development of online peer relationships was a successful resilient coping strategy that supported wellbeing for carers of all resilience levels. Highly resilient carers were able to negotiate formal health and social care systems and services while being authentically themselves within their varied roles and relationships with both the person with dementia and the wider community. Whereas other chapters have focused on a single aspect of the resilience framework, this final data analysis chapter brings together the risk and resilience factors from across each of the three levels: individual, community and society.

## 9.2 Research questions

RQ7 was deconstructed into two sub-questions.

RQ7a What caring challenges do carers describe as a threat to their resilience?

RQ7b What resilient coping strategies do high, and low resilient carers use to overcome caring challenges?

## 9.3 Methods

These research questions were answered through qualitative methods. An overview of the data collection and analysis methods are given in Chapter 3. This is the second analysis of the data derived from the qualitative interviews. Interpretive Description (Thorne et al. 1997) is used to identify the caring challenges that carers faced and to describe the resilient coping strategies they used to overcome these challenges. Differences and similarities in the strategies used by carers with high or low resilience are noted.

Transcriptions were analysed using the same seven-step procedure given in Figure 3-4. A separate analysis was conducted for each research question before the findings were drawn together. At Step 4, (categorisation), caring challenges were identified and categorised, added to the analytic framework (Step 5) and refined into three themes (Step 6). Then steps 4, 5 and 6 were repeated for each caring challenge category to identify the resilient coping strategies carers used. Finally, each participant's resilience score was tracked to quotes within each theme and any patterns were examined (Step 7).

## 9.4 Results

Participant characteristics are shown are shown in Table 4-4.

*Caring challenges that threaten resilience*

Three types of caring challenges were identified. The first challenge carers described was a *loss of self-identity* caused by their changing role and relationship with the person with dementia. Spousal carers described sadness at the loss of 'normal married life' and a feeling of being overwhelmed when their personal identity and that of the shared identity of being part of a married couple were lost.

> *"I'm very upset about the fact that I have had to compartmentalise my marriage. I can't be both things. I'm either one thing or the other. And I'm*

> *no longer a wife. And actually, I don't want to be a carer. I am very resentful about the fact that you know, you're put in a position of care – I'm looking after a vulnerable adult and he is vulnerable so how am I meant to maintain an active sex life with somebody who's vulnerable because actually, to my way of thinking, I'd be interfering with him and actually it feels very uncomfortable" Angela, low resilient carer.*

These changing roles caused carers to lose confidence in their skills and abilities. Carers described uncertainty about their own identity, and how to adapt to this new, unexpected, and sometimes unwelcome role of 'carer'.

The second challenge carers described was in *maintaining social connectedness*. The participants described the distress due to the loss of social networks and friendships:

> *'Friends disappear into the ether. When Alzheimer's is present, friends disappear' Tom, high resilient carer.*

> *'You tell people and the ones you think are going to help you are the ones who don't' Daniel, high resilient carer.*

Prior to the diagnosis of dementia, the participants said they that may have asked friends or family for help and this would have supported their resilience at difficult times. However, the presence of the dementia changed their social support network and as carers became more isolated it became more difficult to seek assistance from friends and family members.

Finally, the third caring challenge identified was *navigating formal services* such as health and social care providers. Some carers had difficulty finding out about relevant services, while others spoke of their struggles to secure person-centred support from statutory services. The assessment process did not seem to be responsive to their needs or preferences.

> *'We've had the ladies from planet social worker, the Galaxy of Fantasy Land come and say … "well oh yes, you must have six weeks break, you can't keep working all the time and he can have respite care"…' Theresa, low resilient carer.*

> *'I feel quite upset that there are huge swathes of some sensitive parts of my life sitting in a filing cabinet drawer somewhere. I think I'm down with social services as unwilling and uncooperative. But I'm not particularly*

> *either thing, I'm just in a situation where I have no choices' Angela, low resilient carer.*

Navigating formal services was reported by all carers as a challenge that specifically tested their resilience. In particular, carers highlighted that they were being offered service-led options as opposed to resources tailored to their needs or wishes. Carers also reported being told that they needed a specific service but that it could not be provided due to limited availability. Some carers also found distressing the apparent lack of empathy displayed by professionals during the process of assessment.

*How do carers respond to these caring challenges?*

Analyses revealed that resilient coping strategies used in response to the caring challenges detailed above occurred in three themes:1) *independence*, 2) *integration* and 3) *faith and fellowship*.

1) *Independence*

Carers used independence as a resilient coping strategy by relying on their own strengths and personal assets and creating separation in their daily lives. In response to the challenge of *maintaining self-identity,* carers kept their own self-identity independent of their caring role by continuing hobbies and interests apart from the person with dementia and putting boundaries around the care they provided. For some, this was achieved by having an identity derived from outside the home. For example, paid employment was a useful coping mechanism in maintaining self-identity, as carers were able to maintain a separate *'work persona'* that was not related to their caring role. Planning for the future and looking ahead to how *independence* and self-identity can be maintained post-caring were also useful.

> *'Who knows what the future holds? He's obviously going to change; the illness is going to change and then my circumstances will change. And when it gets to the point where he's just not safe left on his own all day – he's going to have to go into care. And I know a lot of people at the [support] group clearly look after their spouse right to the end at home. If I give up my job, we won't get money to pay the mortgage. And also if I give up my job – when he has gone, I won't get another job because I'll be too old. People won't want me' Sandra, medium resilient carer.*

For this carer, giving up employment, a role that defined her self-identity, was a step she was unwilling and unable to take. It is plausible that her need for *independence* from caring was driven by the specific challenges of caring for a spouse with young onset dementia. She also needed to be financially independent as her husband was no longer able to work or contribute to household expenses.

*Independence* in response to the challenge of *maintaining social connectedness* was shown through the strategies carers used to carefully choose with whom to share their thoughts, feelings and needs.

> *'Our friendships are like a Venn diagram, aren't they? You have different circles for different things, and they overlap in places and you don't tell everybody the same thing' Angela, low resilient carer.*

This separation of people within a social network was a common experience for carers. There was a wish to keep the 'circles' of friends independent of each other and not be overly reliant on any one person or group. For some carers, the circles became smaller as concerns about 'burdening' friends and family increased. Carers described how the dementia changed relationships. For spousal carers, their emerging *independence* and the change in roles within the relationship that this brought was sometimes something that became apparent over time. *Independence* was not consciously adopted but something that occurred gradually, because the person with dementia lost the ability to be a confidante or share decision making, and often there was no one within the existing support network to take on this role. A resilient coping strategy used to overcome this was to attempt to engage 'experts' or professional counselling services to help them understand their spouse's dementia and their own reactions to it, as the quote below describes:

> *'I have specifically asked for emotional support in perhaps the format of some counselling or whatever but it's just very hard to get anywhere with it really. I was looking perhaps more towards counselling because I need to be able to talk to someone and offload' Sandra, medium resilient carer.*

This preference for a counsellor over a friend was due to concerns about burdening friends, and the boundaries of a professional relationship freed people from this responsibility.

When considering the challenge of *navigating formal services*, some carers valued their *independence* and either did not take up health or social care services or disengaged from them, choosing instead to rely on their own resources.

> *'Never had carers, never had carers in the house, as in [formal] home care or anything like that. Never really trusted any of them to be perfectly honest. And manage just about to sort of cover it all myself' Linda, low resilient carer.*

This approach gave carers a sense of safety as they had control over the care of the person with dementia. It also gave people the opportunity to develop closer relationships with the person they cared for. Carers described an '*us against the world*' feeling when working together with the person with dementia. Being independent of outside influence allowed reciprocity to flourish as there was a shared goal of supporting each other.

### *2) Integration*

The *integration* theme encompassed the process of integrating the role of carer into the person's self-identity, integrating with friends, family and the wider community, and engaging with formal services. Carers who were able to *integrate* their previous self-identity with caring viewed looking after the person with dementia as an extension of the pre-existing relationship with their friend or relative. The label 'carer' was sometimes a barrier to maintaining a sense of self-identity as it had the potential to devalue the primary relationship and identity of the carer. It was, in some cases, rejected by carers who wanted to first and foremost identify with and be identified by their familial role:

> *'I think it's up to us how we perceive our lives and responsibilities. I think the feeling would be a burden if I thought, 'I am her carer and she is taking over my life.' I think not thinking that helps me and I don't feel bad about it' Tuli, high resilient carer.*

Adapting to the changes dementia brought and embracing the evolving relationship was another effective strategy carers used to maintain their self-identity within the caring relationship. Spousal carers spoke about how they continued to find ways to express the warmth of their marital relationship, even in the face of severe dementia:

> *'He always kisses me on the lips, he always kisses everybody else on the cheek. He is still very affectionate and loving. I can't do anything at night, he has to sit next to me and hold my hand. He holds my hand when we go to bed' Pat, high resilient carer.*

These resilient coping strategies effectively maintain the self-identity of these carers primarily as a daughter-in-law and a wife, so familial bonds and relationships are fully *integrated* into the role of carer.

It became apparent from the data that *integration* and social connectedness fell into three main areas: first, there was the *integration* with friends and family; secondly, *integration* with the wider community, and finally *integration* (or lack of integration) with formal service providers. Some carers had been able to replace the losses in their social networks through new connections developed as a direct result of caring for a person with dementia. Carers who participated in Dementia Cafés and support groups could develop a wide social network. However, due to their caring responsibilities, not all carers were able to leave their homes. Some developed a new network of online friends who formed a valued, mutual support group. Carers identified the importance of social media and email as a strategy to maintain or develop new social connections, describing why online relationships are preferred:

> *'The things that have saved me are WhatsApp, you know the social media thing, and the fact that I am quite good at staying in touch with friends: email is useful for that. I'm not a great phoner because I think phoning is intrusive' Angela, low resilient carer.*

Remote messaging was effective as it removed the difficulties of being available to take telephone calls or make visits. Carers were able to maintain longstanding relationships by changing the medium through which they conducted these friendships. Carers described how their existing friends did not always understand dementia or caring, therefore they reached out to online groups on platforms such as Facebook or carer social network forums on charity websites such as the Alzheimer's Society UK. These platforms gave ready access to a new peer group. The amount of engagement carers had with online groups varied: low resilient carers were more likely to observe and not take part, e.g. reading comment threads on carers' forums but not contributing themselves. This 'read only' interaction with the forum was still viewed as valuable as it provided an opportunity to learn from other carers' views and experiences. Others developed significant friendships which extended beyond the initial social network site to private messages and emails. One participant described the depth of these relationships saying, *'she's the best friend I've never met' (Evelyn low resilient carer).* There was a connection and sense of solidarity through this interaction with other carers. It was felt that there was no need to meet face to face as each person understood and accepted the limitations that the other may face due to being a carer.

While dementia-specific resources were useful in some instances, other carers preferred *integration* in a wider community. For some, this was continuing to use community resources such as cafés and groups that they had previously visited. The tension between the change in roles pre- and post- becoming a carer revealed itself as the participants talked about “normal people” who are not carers or associated with dementia services:

> *‘We’re all normal when we go to the Forum, it’s normal life. Everyone we meet knows he’s got dementia. George was stood there talking to a gentleman and they were laughing away, and I thought isn’t that nice?’ Theresa, low resilient carer*

This *integration* with existing community resources provided a counterbalance to dementia-focused services and gave opportunities that carers did not feel were available at specialist settings. Visits to these community settings helped carers to feel connected with the wider world and to continue to feel part of their community.

Within the theme of *integration*, participants spoke about the strategies they used to navigate care services and ensure that their needs were integrated with those of the person with dementia during assessments and care planning. Participants identified that this *integration* required resourcefulness, perseverance, and tenacity. Strategies that supported this were clearly stating both needs and wishes, being prepared to keep asking for assistance, being confident to take issues to senior workers, developing relationships, and having face-to-face contact with the decision makers, as the quote below shows:

> *‘I’m going to ask, ‘can I see the Practice Manager?’, and if she won’t play ball, then I’m going back to the Clinical Commissioning Group. I’m like a terrier’ Tom, high resilient carer.*

*Integration* of the available resources and the individual’s caring goals is paramount. When carers effectively described the *integration* of their own needs with that of the person with dementia to service providers, they seemed more likely to receive the service they desired.

### *3) Faith and Fellowship*

Four out of the five highly resilient carers described their faith or spirituality as a resilient coping strategy. Providing an outlet for emotional distress through prayer and for those who attended, the wider church community could act as *'kind of self-help group' Daniel, high resilient carer*.

Some carers shared their worries within the context of their faith, rather than with family, friends or health and social care practitioners:

> *'I've got a huge faith in God; you see that helps me a lot. I talk to God all the time' Linda, low resilient carer.*
>
> *'My resilience includes God. You can take your problems to God and tell him how you feel' Daniel, high resilient carer.*

This personal relationship with God was described as a positive coping strategy and it provided these carers with a safe space to share their distress. God was seen as both a confidante and companion at times of challenge and carers described how they could share thoughts and feelings in this context that they could not share elsewhere. Belonging to a specific community helped carers to overcome the challenges of maintaining social connectedness and it supported resilience. For some carers, this was achieved through fellowship within a faith group:

> *'I wouldn't ask anybody for anything, if we'd run out of teabags, I wouldn't go and ask for a teabag before. Now, we have church friends, we go every week. There's always one or two that are willing, at the end of the phone anytime we need help' Bertie, high resilient carer.*

Learning to ask for help from the local community was an important resilient coping strategy, one apparently made easier by being part of a group with shared values as in a religious community. However, in the face of caring challenges, some carers described distance from their religious beliefs, even if they had held a prior religious or spiritual orientation. Feeling abandoned by God was identified as a threat to people's resilience:

> *'Well I have lost my faith so … I think, 'well why?' you know, 'why has this happened to us?' You know, 'if there was God… he wouldn't let this happen.' I've always gone to church even from a child but now… It's just gone. It might come back, who knows? Although I enjoy Christmas and Christmas*

> *carols. We're going to a dementia Christmas Carol service at the church'*
> *Jean, low resilient carer.*

Faith and fellowship were resilient coping strategies that some carers struggled to maintain; however, there was a sense that this was a strategy that could be returned to at a later date.

*Are there differences in the strategies used by high and low resilient carers*?

Both groups described similar challenges that threatened their resilience, but for some carers, resilience emerged as they engaged with these challenges. Resilient coping strategies within the *independence* theme were used more frequently by low resilient carers. High resilient carers were more likely to use resilient coping strategies from the *integration theme*. Low resilient carers also used strategies within the *integration* theme but often maintained some distance, for example reading online forum threads but not contributing to them, as described earlier.

There was less demarcation between high and low resilient carers when strategies within the *faith and fellowship* theme were examined. Both high and low resilient carers who discussed their religious or spiritual beliefs used strategies within this theme. It was also noted that one high and one low resilient carer found that their previously held beliefs were affected by their experiences of caring for a person with dementia. For these carers, faith and fellowship were no longer resilient coping strategies they felt they could rely on.

## 9.5 Discussion

This analysis aimed to answer RQ7 through two sub-questions: RQ7a) what caring challenges do carers describe as a threat to their resilience? and RQ7b) what resilient coping strategies do high and low resilient carers use to overcome these challenges? Three challenges were identified. The first was participants having their own identity subsumed by that of being a 'carer', the second challenge was maintaining social connectedness and the third was related to the difficulties they faced navigating formal service providers.

Resilient coping strategies were identified within these three themes: independence, integration, and faith and fellowship. Low resilient carers were more likely to use strategies within the first theme and high resilient carers the second. However, this was not true for faith and fellowship. Both high and low resilient carers used strategies within this theme.

There were some distinct differences in the ways that low and high resilient carers responded to challenges that threatened their resilience. Previous research has found that carers may struggle to adapt or relinquish roles that they associated with their self-identity (Eifert et al. 2015). This was supported by findings from the low resilient carers in the sample, who chose to maintain a clear separation between being a dementia carer and the other roles in their lives. However, the findings extend this by identifying that it is carers with high resilience who often use successful approaches to protect, maintain and enhance their identity. This was achieved by fully *integrating* their role as a carer into their previous roles and identities. This supports previous research which identified that carers who perceived caring to be 'congruent with their sense of self' found a sense of meaning in their caring role (Cherry et al. 2019). The way that carers defined their roles, and the labels that other people applied to their relationship, contributed to resilience. There was marked variation in the tolerability of the label 'carer'. Identifying one person as the carer and designating the other as vulnerable or 'in need' can bring about inferences of burden (Hughes et al. 2013). It also obscures the potential to see the mutuality of caring and the benefits that the relationship brings to both parties, which may ameliorate the negative impacts of caring. On the other hand, self-identifying as a carer may bring benefits such as greater access to services and it may provide opportunities for personal growth (O'Connor, 2007).

All carers used *integration* resilient coping strategies, which aimed to reduce isolation or replace losses in their social network to a greater or lesser extent. Social connectedness, rather than social support or engagement, was identified as a theme. This term describes the carer's presence within their friend and family network and community, but it does not assume that they find this a positive relationship. Dwindling social networks was a common experience, as was discrimination and exclusion. Support from friends, family and service providers can be key to maintaining resilience (Donnellan et al. 2015). There is limited evidence around social exclusion in caring (Greenwood et al. 2018) but it continues to be a priority in driving UK government policy (Carers UK, 2014b).

All participants identified the value of social media and online platforms to maintain or develop social connections. Previous research has identified the potential benefits of online support groups for carers; these include information sharing, increased social contact and emotional support from peers (Moorhead et al. 2013). These findings contrast with a study which found that older adults were reluctant to use social media due to a perceived lack of benefit (Quinn et al. 2016). It may be that as a group of dementia carers, the participants in my sample were more familiar with using the internet to gather information, given that key charities such as the Alzheimer's Society offer online resources targeted at carers.

The degree to which participants engaged with social media varied; online forum use by low resilient carers was characterised by anonymity and 'read-only' participation and, similar to other groups studied, their primary reason for using the forums was information seeking (McKechnie et al. 2014). This passive participation is sometime referred to as 'lurking' and active participants are referred to as 'posters'; both groups are seen as valuable to the online community by group members (Merry and Simon, 2012). Carers used social network platforms such as WhatsApp and Messenger because they overcame barriers of distance and mobility and were seen as non-intrusive. They are a valuable tool for carers to maintain their social connectedness, and other research has shown that social network sites also contribute to feelings of wellbeing (Khosravi et al. 2016). Carers did not need 'real world' relationships in order to feel connected. These findings align with findings from other diagnostic groups such as people living with mental illness (Naslund et al. 2017).

Resilient coping strategies within the *integration* theme were characterised by balancing the roles, needs and wishes of both the person with dementia and the carer. This was particularly true when responding to the challenge of navigating formal services. There is an acknowledgement that high-quality and consistent care and support benefit the health, wellbeing, and resilience of unpaid carers (NICE 2018a), but carers face significant challenges accessing this support. Accessing resources and support is deemed a key resilience trait (Donnellan et al. 2015). Previously, a lack of information was a significant barrier to carers using support services (Brodaty et al. 2005), but since that earlier research was published the implementation of the Care Act 2014 (HM Government, 2014) has placed a statutory requirement on local authorities to provide advice and information to families, and only one family said they did not know about support services. The availability, affordability and acceptability of services were obstacles to service use for both high and low resilient carers. Some carers felt the services they were offered did not align with their needs, wishes or long term goals. These findings reflect those of Peel and Harding (2014), who found that carers continued to be confused by the care system, which was often rationed and difficult to access.

Faith and fellowship supported carers across various challenges. Religiosity has been associated with resilience (Deist and Greef, 2015). Faith and fellowship were important for both low and high resilient carers who derived both practical and emotional support from their faith communities. Personal spirituality supported carer self-identity and participation in collective worship and fellowship provided opportunities for social connectedness. For some, the personal relationship with God facilitated the resilient coping traits of self-control and personal growth as it provided comfort and a non-judgemental place to share their distress. Agli et al. (2015) found that faith and spirituality 'enriched coping strategies'. Herrera et al. (2009) found that carers who had positive views about religion and spirituality used their faith to promote acceptance and manage their stress. However, carers who described negative religious coping, such as feeling abandoned by God, were more likely to report greater distress. Recent research examining cognitive behavioural and spiritual counselling interventions led by Faith Community Nurses has shown some promising results in reducing negative effect and promoting self-care (Kazmer et al. 2018). The role of maintaining one's beliefs and faith in the context of dementia caring was identified as a research priority by the Alzheimer's Society Research Network (Alzheimer's Society 2012). However, there continues to be a lack of research in this area and specific research is required to understand the role of faith and fellowship in supporting carer resilience.

Although this analysis addresses a gap in the understanding of resilient coping strategies, it has some limitations. The sample was drawn from a predominately rural area of England UK and therefore it may not be representative of carers in highly urbanised areas. The use of the BRCS and the grouping of carers may be too simplistic, as carers may demonstrate resilience in some circumstances and not others or they may have fluctuating levels of resilient coping dependent on other contextual factors that are not captured in the standardised measurement.

This analysis has identified salient stressors and corresponding resilient coping strategies. These have implications for the response to the mental health needs of informal carers of people with dementia. Voluntary services such as Dementia Cafés and faith groups can provide an important resilient coping resource for informal carers. Similarly, health and social care practitioners can support carers to manage the challenges identified through interventions that promote the use of resilient coping strategies. Future interventions which support carers to develop and use resilient coping strategies that maintain their sense of self and social connectedness and enable them to effectively negotiate systems and services may help them to overcome care-related challenges.

## 9.6 Summary

This final analysis has described factors that bring risk or promote resilience for individuals providing care for a friend or relative with dementia. It has identified the complexity of changing identities and roles that can threaten carer wellbeing. Low resilient carers used strategies which sacrificed their previous identity to the new role of dementia carer or caused them to compartmentalise their lives. In contrast, highly resilient carers were able to successfully maintain a strong sense of identity, integrating the role of carer into their own sense of self. All carers described feelings of social isolation, including those with a high level of engagement in community activities. However, remote relationships conducted via email or social network sites were valued and helpful to both low and high resilient carers. Dealing with statutory services was a source of stress and required ongoing resilience to secure the best outcome for the carer and person with dementia.

It is hoped that the findings of this analysis may facilitate recognition that resilient coping strategies can support carers to maintain their health and wellbeing and continue to care. The next chapter presents the data synthesis of all the analyses within the thesis.

# 10 GENERAL DISCUSSION

## 10.1 Foreword

This chapter includes a summary of the key findings of each analysis and the presentation of data synthesis using a mixed-methods matrix. An outline of the strengths and limitations and what could have been done differently is presented. The contributions of the research to the scientific literature, as well as the clinical, policy and theoretical implications of these findings for carers and health and social care services are discussed. This section ends with recommendations for future research and the overall conclusions of this programme of research.

## 10.2 Summary of aims and methods

The overarching aim of this programme of research was to explore resilience in carers of people with dementia. The importance of supporting carers is acknowledged by policy makers, clinicians, and families themselves (James Lind Alliance, 2015). Carers provide invaluable support to the individuals they care for and an invaluable service to society (Alzheimer's Research UK, 2015). Caring is associated with multiple morbidities (Lethin et al. 2017) but distress and ill-health are not an inevitable outcome of caring. Identifying the characteristics and context of those carers who thrive in their caring role is important to enable us to better support those who are merely surviving.

A mixed-methods study using explanatory sequential design (Creswell and Clark, 2017) was undertaken to understand the interplay between individual carer characteristics, social support, and resilient coping. The resilience framework (Windle and Bennett, 2011) was used as the theoretical underpinning for this study. Quantitative methods were used to first assess the role of resilient coping in carer wellbeing and psychological distress (Chapter 6) and, secondly, to examine the interplay between resilient coping and social support (Chapters 7 and 8). Qualitative methods were used to add context to and explain the quantitative findings by answering research questions about how carers conceptualise resilience (Chapter 5) and the specific resilient coping strategies carers use to overcome caring challenges (Chapter 9). In order to operationalise the resilience framework in caring relationships (Windle and Bennett, 2011), the findings from both analyses were mapped onto the framework (see Figure 10.1).

## 10.3 Overall conclusions

**Chapter 5: Coping but not allowing the coping to be everything**.

Research questions:

RQ1a Do carers’ conceptualisations of resilience vary from the definitions found in the scientific literature?

RQ1b What differences and similarities occur in conceptualisations of resilience between carers with high, medium, and low resilience scores?

RQ6 How does carers’ perceived level of resilience as described at interview compare with their level of resilience when measured on a standardised tool?

In response to RQ1a, the findings showed that the carers’ definitions do align with published definitions in several key areas, namely flexibility, adaptability, and personal growth (Joling et al. 2017). Additionally, this research has added to the current scientific literature by describing carers’ priorities and concerns, which they felt either promoted or hindered their resilience. For example, prioritising self-compassion – specifically celebrating successes and acknowledging personal limits, helped carers to feel more resilient. Carers also emphasised how resilience may fluctuate and co-exist with distress. This contradicts studies where resilience is considered an outcome and is defined by the absence of distress (Donnellan et al. 2015). It supports instead the literature conceptualising resilience as a process (Luthar et al. 2000).

When answering RQ1b, the findings showed that highly resilient carers described an active response to challenge, characterised by problem solving and engaging with a support network. Low resilient carers spoke of their resilience being shaped by factors outside their control and they perceived resilience as being able to just ‘keep going’ despite ongoing challenges. In contrast, highly resilient carers were less influenced by external factors, instead suggesting that having (and living by) particular values led to resilience

In response to RQ6, when comparing measured and perceived levels of resilience, there were discrepancies between the two ratings for seven out of 13 carers. Given the earlier findings of differences between academic and lay definitions, it may be that the resilience tool measured different characteristics to those that the carers felt described resilience. Equally, where carers believe that their resilience is low but they score in the high range of the rating scale, it may be that these individuals employ the resilient coping strategies measured by the tool but these actions do not correspond to personal feelings of resilience. The participants described the experience of friends, family members and service providers making an erroneous assessment of their resilience and this having negative consequences, such as fewer offers of help. Carers in this situation felt that people made the assumption that they were able to cope. This highlights the need to support carers to identify and describe their own needs within assessments for example, by using the CSNAT Approach (Ewing et al, 2015). This question gave context to the following chapters and highlighted how different understandings of the concept may influence the carers' experience.

### Chapter 6: What role does resilient coping play in carer wellbeing?

This quantitative analysis was focused on the individual factors of the resilience framework and it tested the following hypotheses:

1) High resilient carers will report less distress than carers with lower resilience.

2) As carer distress increases, carer wellbeing will decrease, and the presence of resilient coping will mediate the relationship between carer distress and wellbeing.

The results supported the first hypothesis and showed that carers with high resilient coping have significantly lower scores on measures of depression, anxiety, stress, and burden when compared to those with low resilient coping.

The second hypothesis was partially supported as resilient coping acts as a partial mediator in the distress-wellbeing relationship, where the presence of resilient coping lessens the impact of each distress variable (depression, anxiety, stress, and burden) on subjective wellbeing.

However, the data also showed the heterogeneity of carers' experiences of psychological distress: reporting symptoms of depression, anxiety, stress, or burden was not universal. The results aligned with other published work (Southwick et al. 2014, Wilks and Croom, 2008) showing that highly resilient individuals can also report high levels of distress. This seems to indicate that resilience is a wider construct than simply the absence of distress.

These findings highlight the value of promoting and maintaining resilient coping in informal carers as it could be a useful strategy to reduce the morbidity associated with caring for a person with dementia. Resilience cannot be achieved in isolation (Rutter, 2012) and the resilience framework (Windle and Bennett, 2011) highlights this. The community level of the framework suggests that social support has a role to play in resilience as well. The next chapter examined carers’ use of a social support setting, specifically Dementia Cafés.

### **Chapter 7: Social support settings and resilience**.

In this question, the focus shifts from individual factors associated with resilient coping in carers, to carers’ use of community resources. The analyses tested the hypotheses that:

1) Café attendees will have greater resilience, subjective wellbeing, and perceived social support than non-attendees.

2) Specific socio-demographic characteristics will predict café attendance.

The first hypothesis was partially supported as the results showed that carers who attended a community-based Dementia Café had greater resilience and higher wellbeing scores than carers who did not attend. No differences between attendees and non-attendees were detected with regard to perceived levels of social support, a result that aligns with findings from another study conducted at a Dementia Café within a clinical setting (Merlo et al. 2018). However, this lack of difference in perceived social support was an unexpected finding, as previous qualitative studies have found Dementia Cafés to be a source of social support for informal carers. As this is a cross-sectional analysis, causality cannot be determined: either cafés support carer resilience or resilient carers are more likely to attend a café.

In response to the second hypothesis, differences were noted when comparing the socio-demographic data of café attendees and non-attendees. In this analysis, 75% of the female participants attended a café whereas only 48% of the male participants were café attendees. However, there were far fewer men in the total sample so these results should be interpreted with caution. When all factors were examined together, only subjective wellbeing and leaving school with 12 years' or less formal education predicted attendance at a café.

These findings suggest that the café model may not have universal appeal, or the structure may be inaccessible for some carers. Additional forms of community-based post-diagnostic support should be considered to promote carer resilience and social support and improve equity of access across all carer groups. This chapter showed that an individual social support setting cannot necessarily meet the specific needs of all carers and that cafés may not provide an increased level of social support. The resilience framework (Windle and Bennett, 2011) places social support within the community level of resources, which may bring risk or resilience to the carer but it does not differentiate between social support from group settings or from individuals. Therefore, the next analysis of the quantitative data examined the role of social support from friends, family and neighbours.

### Chapter 8: Domains of social support and resilient coping.

This chapter explored the social support that carers perceived they had available to them and it tested the following hypotheses:

1) Carers who report high resilient coping will have greater perceived social support.

2) Specific types of social support will have greater influence on resilient coping.

The first hypothesis was supported; carers with high resilient coping perceived that they had more frequent access to all forms of social support than carers with low resilient coping scores. Four domains of social support (emotional/informational, tangible, affection, and positive social interaction) were examined. Carers reported that they felt affection was the type of social support most available to them. The domain perceived as least available was tangible support: some carers even reported that this domain of social support was 'never' available to them. This result supports findings from other studies which highlight that carers of people with dementia are at greater risk of social isolation and have limited or declining social networks to call upon for support (Clay et al. 2008; Han et al. 2014).

However, the second hypothesis was rejected; no specific type of social support predicted high resilient coping. This contrasts with qualitative data, which indicated that resilience is associated with emotional/informational support and tangible support (Donnellan et al. 2015).

The results from this chapter also shed light on the socio-demographic characteristics that predicted resilient coping. My findings show that female carers had higher resilient coping scores than their male counterparts. This contrasts with the findings from a large published study (Kocalevent et al. 2017) which identified that men report marginally higher resilient coping scores than women. This suggests that the differences in resilient coping between genders may be small and context specific.

This analysis highlights the importance of enabling carers to develop or maintain a multi-function social support network, which can contribute to their resilience and potentially act as a resource to support resilience, as identified within the community level of the resilience framework (Windle and Bennett, 2011). The final analysis of the thesis explored risks and resources across the three levels of the resilience framework (individual, community and society) through qualitative methods.

### Chapter 9: What resilient coping strategies do informal carers use to overcome caring challenges?

This second analysis of the qualitative data investigated the resources for 'risk or resilience' as identified in the resilience framework (Windle and Bennett, 2011), Figure 2-1.

The research questions for this analysis were:

RQ7a What caring challenges do carers describe as a threat to their resilience?

RQ7b What resilient coping strategies do high, and low resilient carers use to overcome these challenges?

The challenges carers described were considered 'risks' and the responses they used to overcome these challenges were identified as resilient coping strategies. Specific challenges highlighted by carers were *maintaining self-identity, social connectedness* and *navigating formal services*. These align with the three levels of the framework (individual, community and society) (Windle and Bennett, 2011).

The resilient coping strategies that carers used in response to these challenges were described in three themes: *independence*, *integration* and *faith and fellowship*. *Independence* was discussed in terms of the carer's self-identity being independent of their caring role, i.e. by maintaining interests and friendships not related to or associated with caring for the person with dementia or putting boundaries around the care by identifying situations where the carer would relinquish care. Equally, *independence* as a resilient coping strategy was also described in terms of limiting the information shared with friends, family or employers and a reduced level of engagement with health and social services. Making decisions and managing all of the care tasks independently were seen (mostly by low resilient carers) as positive resilient coping strategies as they gave a sense of control in situations where there often seemed to be a lack of choice for the carer.

*Integration* strategies were more likely to be used by high resilient carers. These included integrating the caring role with the previous relationship with the person with dementia, maintaining integration with previous social networks, seeking out new social connections and securing services from health and social care providers. This integration of sense of self and the new role of carer supports previous research which identified that carers who perceived caring to be ‘congruent with their sense of self’ found a sense of meaning in their caring role (Cherry et al. 2019). Also important for both high and low resilient carers was the use of online platforms, which supported people’s independence by enabling them to find sources of information and integration and maintain or develop social connections. This supports the findings of Moorhead et al. (2013), who found that online support groups were useful for carers.

*Faith and fellowship* were important for both low and high resilient carers. Individual spirituality supported carer self-identity and fellowship within a religious setting and provided opportunities for social connectedness.

Future interventions which support carers to develop and use resilient coping strategies that maintain their sense of self, social connectedness and enable them to effectively negotiate systems and services, may be beneficial for the health and wellbeing of informal carers. It is important that health and social care providers identify the specific caring goals for each individual, as these may vary between carers with high and low resilience.

## 10.4 Data synthesis: The resilient carer

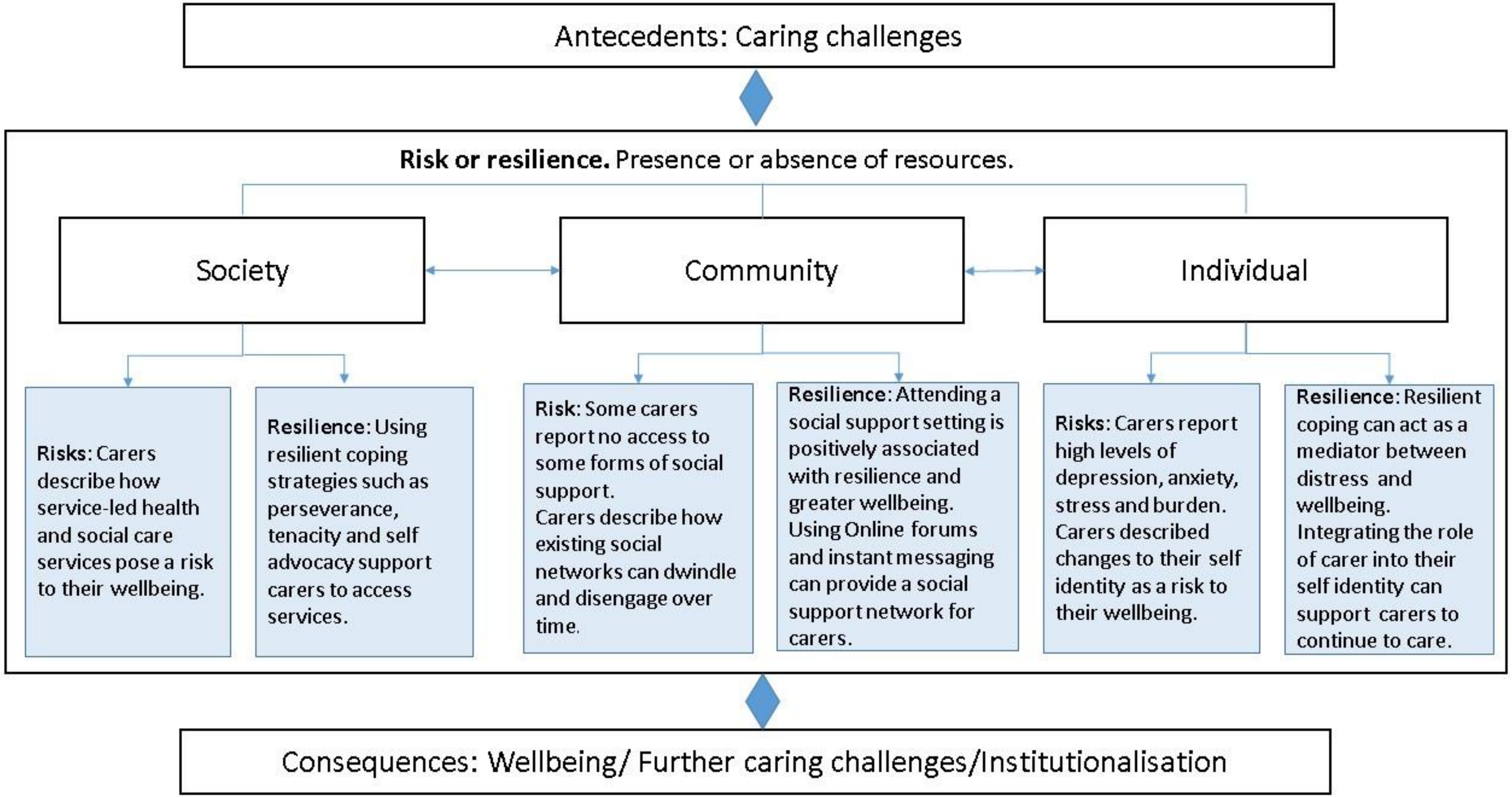
The above section has given a summary of each chapter analysis. These have contributed individual findings, but an integrated view can facilitate and contribute to a wider understanding of resilience in providing care for a friend or relative with dementia. Data were synthesised using a triangulation protocol (Figure 3-1) and a mixed-methods matrix (O’Cathain et al. 2010), as described in Chapter 3. An extract of the data synthesis matrix is given in Appendix 12.14 and an overall summary is given in section 10.5. These findings were then mapped to the resilience framework (Figure 10-1).

Overall, the studies presented in this thesis have demonstrated that, on balance, carers with higher resilience tend to: (1) report less distress, (2) have access to a supportive social network and (3) have greater integration with community and societal resources. Carers with lower resilience report higher levels of depression, anxiety, stress, and burden. They describe social support as insufficient or absent and therefore use more independent resilient coping strategies rather than draw on external resources. Resilience was found to be a protective factor but one that could not eliminate distress or diminish the challenges associated with caring. It may however aid recovery and help the carer to overcome setbacks or to approach new challenges in a more positive way.

Importantly, this thesis demonstrates that this dichotomy of high and low resilience is not static. Carers experience periods of greater or lesser resilience dependent on a range of personal and contextual factors related to the care of the person with dementia. Resilience may be developed over time, with carers describing ‘growing into resilience’ and this thesis supports the position that resilience can be conceptualised as a process of personal growth. An individual can develop resilience as they learn to apply strategies, gained in earlier periods of challenge and adversity, to their role as an informal carer.

The literature identifies resilience as ‘ordinary magic’ (Masten, 2014b) and everyone has the capacity to develop and demonstrate resilience. The thesis’ findings clarify and expand this within the context of caring for people with dementia. In line with Masten (2014b), this analysis found that all carers demonstrated some resilient coping strategies. Low resilient carers used individual strategies that focused on self-reliance and compartmentalising the caring role from other aspects of their lives. These strategies may promote the wellbeing of the person with dementia and the carer’s ability to care in the short term. However, this self-sufficiency may put the carer at greater risk of burnout in the long term.

Highly resilient carers used resilient coping strategies that enabled them to successfully maintain a strong sense of identity, integrating the role of carer into their own sense of self. This enabled them to acquire support for both themselves and the person with dementia.



**Risks**: Carers describe how service-led health and social care services pose a risk to their wellbeing.

**Resilience**: Using resilient coping strategies such as perseverance, tenacity and self advocacy support carers to access services.

**Risk**: Some carers report no access to some forms of social support. Carers describe how existing social networks can dwindle and disengage over time.

**Resilience**: Attending a social support setting is positively associated with resilience and greater wellbeing. Using Online forums and instant messaging can provide a social support network for carers.

**Risks**: Carers report high levels of depression, anxiety, stress and burden. Carers described changes to their self identity as a risk to their wellbeing.

**Resilience**: Resilient coping can act as a mediator between distress and wellbeing. Integrating the role of carer into their self identity can support carers to continue to care.

**Figure 10-1** Thesis findings mapped onto the Resilience Framework

## 10.5 Overall strengths and limitations of the research programme

### Reflections on alternative approaches to the research questions.

As the previous chapters (5, 6, 7, 8 and 9) have described the specific strengths and limitations associated with the methodological choices taken to answer each research question, this section outlines the overall strengths and limitations of the thesis and how these relate to the overall conclusions drawn. Limitations are discussed in the context of the potential risk of bias, and alternative approaches that could have been used are described.

### Methods and methodological considerations

For this research, a mixed-methods approach was taken as the constructs of resilience, subjective wellbeing and social support are complex and require a broader exploration rather than that offered by a single measurement method. Quantitative results have been complemented by the qualitative findings and this enabled the generation of stronger evidence through the convergence and corroboration of findings (Polit and Beck, 2008). For example, the quantitative findings showed that some carers perceive that they have very limited access to social support, while the qualitative findings described why this may be the case, i.e. some carers choose to withdraw while others are abandoned by their social networks.

One strength of the research is the mixed-methods two-phase sequential design. The preliminary data analysis of phase one (quantitative data) supported the development of the interview schedule for phase two. Specifically, the design allowed further exploration of the unexpected findings around social support settings and resilience and the perceived lack of availability of social support that carers described. Sequential phasing also supported recruitment, as over 30% of the survey respondents volunteered to take part in the follow-up interview. This provided a pool of potential recruits and facilitated the purposive sampling to ensure that a broad range of participants were involved in the qualitative phase.

A limitation of the sequential design is the need to bring phase one recruitment to an end to allow time for preliminary data analysis prior to starting phase two. This was a pragmatic decision based on the time constraints of the PhD programme. Allowing the quantitative phase to run for longer may have allowed more carers to take part and provided greater power to the statistical analyses. However, if phase one was allowed to extend too long, the research may have lost momentum as those participants who agreed to be contacted for follow-up interviews may subsequently have lost interest or their circumstances may have changed (Whittingham et al. 2016). This was the case for one potential participant who became too physically unwell to take part in the follow-up interview.

## Phase one - Quantitative analyses

A limitation of the quantitative analyses was that their approach was cross-sectional and measured psychosocial outcomes at one point in time, which prevented the exploration of possible causality or prediction of long-term outcomes. It may be useful to take repeated measures of resilience throughout the caring trajectory to gain a more in-depth understanding of how the level of resilience fluctuates within one individual over time. This may help in the timely targeting of resources and interventions to support carers.

Although the completion rate for the survey was good (74%), as stated earlier, it is not possible to ascertain the reach of the information about the survey. An alternative approach would have been to have one point of entry into the research, i.e. not publicising the research with other parties. However, this may have limited the range of venues available to make contact with carers. The collaborative approach to recruitment with the Alzheimer’s Society and Healthwatch was a strength as it raised the profile of the work and facilitated dissemination. It would also have been helpful to have a system to follow up participants who had received but not returned a survey. This is a limitation inherent in the research process itself, as the nature of the cafés and advertising system (e.g. online approach) did not allow personal identification of attendees before the consenting process. A financial incentive may have increased participation (Resnik, 2015) but unfortunately there were no funds available for this.

### Risk of bias

#### *Setting*

The majority of recruitment took place in Norfolk in the East of England. This is an area of the UK with one of highest rates of dementia in the UK. The North Norfolk parliamentary constituency is ranked the third highest in the UK for the number of people living with dementia. 2.44% of the population of North Norfolk have a diagnosis of dementia (Alzheimer's Research UK, 2017). Given the high rates of dementia in the local area, it may be that carers have better access to information and services to support them in their caring role than in areas with lower rates.

Dementia Cafés were used as a key recruitment setting; at the time of the research there was a review of social care funding nationally and subsequent cuts were planned for to local service provision (Ford et al. 2014). Some of the cafés I visited were being reviewed and evaluated to determine whether their funding would continue. Although the purpose of the research was made clear – and was in no way related to the ongoing funding of services – carers may have seen taking part in the research as a way to demonstrate their attendance and commitment to the Café.

Although additional efforts were made to reach other carers, including the use of a national online forum, there was a bias towards individuals who self-identified as a carer and who were in contact with some form of carer advice or support service. Given that engaging with support services is a potential indicator of resilience (Donnellan et al. 2015), this research may be skewed to and have included more resilient individuals.

*Recruitment and sample size*

The sample of carers who took part in this research had broadly similar socio-demographic characteristics to carers nationally (Wimo et al. 2013): a)  more women than men took part; and b) the majority of carers were retired and looking after a spouse with dementia. While my sample was similar to other national studies, the gender and age biases need to be acknowledged. This has been discussed for each quantitative analysis within the respective chapter and it was highlighted that the skewed sample may have increased the risk of a type two error in relation to the socio-demographic findings. Of greatest importance to the thesis' overall findings is the likelihood that the finding that female carers are more resilient than their male counterparts may be due to such an error.

The cross-sectional survey failed to recruit equal numbers of men and women. Fewer male carers completed the survey (33%). There are over 51, 000 male carers aged over 85 in the UK, this is the only demographic of carers where men outnumber women (Carers UK and Age UK, 2015). Older male carers have been identified as the group most likely to delay asking for help until they reach crisis point (Hughes et al. 2017). This meant they may have been less likely to access settings and venues where this study was advertised. Publicising the study via GP practices or community nursing teams may have improved the visibility of the study to older male carers (McMurdo et al. 2011) and improved recruitment from this group.

The sample size was also small; the target sample size was not met, resulting in the analyses having reduced power. The results overall should therefore be interpreted with caution. Effect sizes were calculated for all quantitative sub-studies and details of this limitation are discussed in each chapter. In addition to the data discussed within the chapters, information about neuropsychiatric symptoms and the functional dependency of the person with dementia was also collected. The Cambridge Behavioural Index-Revised (CBI-R) (Wear et al. 2008) was used to measure symptom frequency and how ‘bothered’ the carer was by the symptom. Functional dependency was measured using the Bristol ADL Scale (Bucks et al. 1996). This data was to be used to test the hypothesis that carers with higher resilience experienced less bother, when controlling for symptom frequency. There are a number of sources that recommend 10 observations per covariate (Peduzzi et al. 1996) and the sample size did not meet this minimum threshold. Harrell (1985) suggests a process of ‘dimension reduction’ to reduce the number of covariates. A major criticism of this approach is that it has the potential to lose relevant data as covariates are removed or combined (Cook, 2018). The responses to these questionnaires were also poor and did not meet the minimum threshold for inclusion into the analysis. Therefore, as the risk of running a flawed analysis was high it was decided to accept the limitations of the dataset, and not use data from the CBI-R or Bristol ADL Scale. This research question was removed from the protocol. Instead, the research focused exclusively on factors relating to the carer.

Three methods were used to recruit potential participants to phase one. It is a limitation of the procedure that the survey did not record where the participant was recruited, either face to face, online or via a letter sent by a partner organisation. This prevented any analysis of either the most effective recruitment method or whether carers with different socio-demographic characteristics came to the study via different routes.

Additional data could have been collected from participants, specifically in relation to physical health. Given that carers consistently report negative impacts of caring on their physical health (Carers UK, 2018a), this is a limitation of the research as it prevented exploration of whether these variables had an impact on resilience or attendance at a social support setting. No data was collected on the ethnicity or socio-economic status of participants and therefore no analysis of how these factors may impact resilience could be conducted.

*Questionnaires*

Data collection questionnaires were self-reported by the carer and therefore based on a subjective account of their perceptions of resilience, wellbeing, social support, and the needs of the person with dementia. A limitation was the absence of triangulation with clinical data in relation to the diagnosis of dementia. This limited the opportunity to make comparisons between groups of carers by type of dementia. It is likely that type of dementia may have a bearing on resilience as it has been shown to have an impact on other measures such as carer burden (Liu et al. 2017). An alternative strategy would have been to recruit participants via primary care, neurology or mental health services and seek to include relevant data from their clinical records or conduct face-to-face assessments, which could include objective measures of the cognitive functioning of the person with dementia and the health and wellbeing of the carer. However, this process would have required consent and engagement from the person with dementia and placed greater burden on the carer. Given that the focus of the research is on the carer and being mindful of the time constraints of the PhD, these additional processes may have limited participation without bringing sufficient benefits to the research. A further limitation is the lack of a gold standard tool to measure resilience as far as I am aware this is the first use of the BRCS with carers of people with dementia.

*Missing data*

As discussed in section 3.10, missing data on the psychosocial measures were assumed to be missing at random and thresholds were set for each questionnaire based on the author's guidelines, where possible. Where missing data were above the threshold identified for each specific questionnaire, data were deleted list wise, which reduced the number of participants included in some analyses.

In Chapter 8, the BRCS score was dichotomised to provide high and low resilient groups. This gave two groups of roughly equal size to investigate the relationships between social support and high/low resilient coping. When used in this way, the BRCS can screen for low resilience (Sinclair et al. 2016) and identify a target group for intervention. However, (MacCallum et al. 2002) argue that dichotomisation does not provide two groups with distinct characteristics but creates 'essentially arbitrary groups.' There are considerable limitations to this approach, including a reduction of power, effect size and the loss of information about individual differences

(MacCallum et al. 2002). An alternative approach would have been to conduct linear regression analyses, which would have reduced these limitations.

### Phase two – Qualitative analyses

The qualitative approach used in Chapters 5 and 9 was appropriate for the exploratory nature of the studies' aims, i.e. to explore carer conceptualisations of resilience and understand the specific resilient coping strategies they use. However, a limitation of the qualitative phase was the small sample size; although efforts were made to engage carers with a broad range of experiences, a notable omission was the lack of young adult carers, who may potentially have had different experiences to the participants who took part. As the subset of carers was drawn from the phase one sample, the issues of bias in the larger group must be considered, although steps were taken during sampling to tackle some of the issues, e.g. the skew towards older female carers was addressed in the second sample.

No record was made on the final anonymised data set of which participants volunteered to take part in the interview. Therefore, no retrospective analysis was possible to compare those who volunteered for further participation and those who did not. Consequently, it is not known whether this subset of people had any specific characteristics that made them more likely to participate than those who chose not to have further contact. Selection bias in the recruitment of the phase two sample may also have occurred, as the sample used in the qualitative analyses comprised people who had already been invited to take part in the survey. This potentially excluded people who would have consented to an interview but did not wish to complete the survey. An alternative strategy would have been to recruit people independently for each phase of the research.

An alternative to the use of face-to-face interviews would have been to use telephone interviews. This would have potentially provided the opportunity to recruit from a wider geographical area and it would have eliminated travel time and costs. It may also have increased the disclosure of the participants' thoughts and feelings due to greater perceived anonymity (Oltmann, 2016). However, the choice to use face-to-face interviews provided the opportunity to collect rich data about the context of care. It facilitated building a rapport and enabled me to respond to both verbal and non-verbal responses, so worked well in this instance.

Member checking, i.e. providing participants with the opportunity to review and approve aspects of the interpretation of their data, can be a useful tool for validation and assessing whether data analysis is aligned with the participants' experience

(Curtin and Fossey, 2007). This research programme did not make use of member checking due to time constraints, the nature of the phenomenon being studied and the characteristics of the participants. Resilience is dynamic and changeable (Southwick and Charney, 2018) and how participants describe their own resilience may vary from day to day. Still, this research programme has provided a snapshot of carer resilience at one point in time and within the timeframe available for the PhD programme. Equally, caring is unpredictable, and participants' perceptions of resilience and support may vary according to the current care situation. Likewise, dementia is a terminal illness, and two carers were bereaved in the weeks after the interview. Returning to these participants could have caused distress, given the frank nature of their interviews. One carer also died. A lack of member checking may be a limitation but as ontologically this research design acknowledges multiple realities, it has not compromised the overall aim of the research.

### Strengths of the research programme

The insights from the qualitative data gave context to the quantitative results, exposing the specific challenges that carers face in managing their own mental wellbeing and engaging with wider support networks. The quantitative findings highlighted deficits in social support and experiences of psychological distress. Describing the key components of resilience most important to carers and identifying specific resilient coping strategies can inform the development of resilience-focused interventions to address these issues.

The specific focus on resilient coping within the programme worked well within the sequential design as carers could be identified by their resilience score and comparisons made. Resilient coping is a growing area of research and is being examined in different vulnerable populations, including military veterans (Van Voorhees et al. 2018). This research contributes to the growing knowledge base around resilient coping in informal dementia care.

## 10.6 Theoretical implications

This thesis sought to operationalise the resilience framework (Windle and Bennett, 2011), Figure 2-1. Therefore, the research questions, variables measured and outcomes evaluated were guided by, but not restricted to, those outcomes identified within the framework. The results have contributed to a deeper understanding of each level, and the antecedents, risks or resources and consequences of the original framework. Individual-level psychological resources are discussed in

Chapters 6 and 9, and community and societal resources are discussed in Chapters 7, 8, and 9. These findings are drawn together and specific findings related to risks and resilience factors are mapped to the resilience framework in Figure 10.1.

Consequences identified in the framework are ‘wellbeing, further caring challenges or institutionalisation’. However, the findings from across the research questions highlight the temporal nature of both wellbeing and further caring challenges as consequences. Carers’ feelings of resilience may fluctuate in response to individual factors such as physical wellbeing, the day-to-day challenges of providing care or situations outside the context of care. Equally, compromised wellbeing was both acknowledged and accepted as a possible consequence of caring, but one that was seen as transient.

The quantitative findings showed that resilience and psychological distress can co-exist. Resilient coping was a partial mediator but did not eliminate the reporting of depression, anxiety, stress or burden symptoms. ‘Bouncing back’ and recovery were seen as being indicative of resilience by carers. Additionally, ‘further caring challenges’ were seen as inevitable consequences that could not be avoided despite the availability of resources that facilitated resilience.

Carers applied different resilient coping strategies to the caring challenges. Some responded by having an open flexible approach, while others put boundaries around what they would and would not do in the context of providing care for the person with dementia. These were both considered resilient responses. However, the consequences for the person with dementia were potentially very different. Carers in the high resilient group responded to each new challenge by adapting their approach and they spoke positively about the future and the likelihood that they would continue to care for the person with dementia through the duration of the illness. Carers with lower resilience spoke of limits to the challenges they could respond to and future plans tended to include engaging increasing levels of formal support and the planned ‘institutionalisation’ of the person with dementia. The heterogeneity of resilient coping strategies described by carers further highlights the need to identify each carer’s own goals, whether that be a wish to continue to provide care at home, or to choose to stop providing direct care, and support the person’s transition into a care home.

## 10.7 Policy and practice implications

This research has practical implications for health and social care staff and stakeholders wishing to improve wellbeing and the experience of providing care for families with dementia.

Academic definitions of resilience focus on the absence of distress and adaptive coping. In line with another study which included family carers (Joling et al. 2017), I found that carers understand resilience in terms of balancing their wish to do everything for their relative with the reality that sometimes this is not possible. Equally, carers prioritised maintaining a strong sense of self amidst the changing relationship with the person with dementia. Labels and terminology used by service providers to describe relationships, i.e. using ‘carer’ or ‘vulnerable adult’ instead of referring to the person by their relationship (e.g. husband/wife), are not always welcome and can negatively impact on the carer’s self-identity. One solution may be to discuss both terms (e.g. carer, spouse) with the individual while acknowledging separation of the two identities and using their preferred terminology.

***Recommendation 1*: Frontline health and social care staff supporting carers should be alert to how they define the roles and relationships within families and caring dyads and avoid using terminology that may devalue this, e.g. not referring to a family member as a carer if they do not identify as such**.

The identification of carers with low resilient coping could facilitate the targeting of resources to more vulnerable individuals where the caring relationship is at risk of breaking down (López-Pina et al. 2016). The findings have shown that assessment of resilience on a standardised scale may not match the carers’ own perceptions of their resilience and how overestimations of resilience may lead to a lack of offers of support. The findings presented demonstrate how some carers have negative experiences when trying to engage with support services. This was especially true where this disparity between subjective and objective assessment of resilience existed.

***Recommendation 2*: Health and social care staff should consider how carers may present as resilient, but this may be rather superficial and belie a greater need for support. Assessment should therefore aim to understand the carers’ own perceptions of their ability to continue to care for the person with dementia**.

There has been a confirmed shift in UK policy with regard to supporting carers since the first legal recognition of the fact that carers have their own care and support needs (HM Government, 1995), along with a growing recognition that interventions to promote carer wellbeing benefit both the individual and wider society. Carers may have developed a range of resilient coping strategies as a response to earlier times of adversity or challenge. Where this is not the case, focusing on the development and maintenance of resilient coping skills may support carers to provide care for their relative for longer and reduce their risk of experiencing some of the negative consequences associated with caring.

***Recommendation 3*****: Frontline staff should help carers to understand that resilience may fluctuate, and that periods of low resilience can be followed by recovery. Carers should be supported to draw on and apply assets and strategies that they have previously developed in other contexts to support them in their caring role.**

***Recommendation 4*****: Specialist carer support practitioners, e.g. Admiral Nurses, should consider the use of approaches that promote the development and use of effective resilient coping strategies in carers. Intervention should focus on the resilient coping skills of creative problem solving, emotional regulation, self-compassion and replacing losses encountered through caring**.

This thesis has contributed to the growing evidence of a link between faith, spirituality, religious practice, and resilience. It has identified that both personal spirituality and fellowship within a wider faith community can support carers' resilience.

**Recommendation 5: Leaders of faith communities may benefit from support from health and social care practitioners to consider ways in which they can effectively identify and provide ongoing pastoral care to carers within their congregation and their wider community**.

## 10.8 Research recommendations

This programme of research has offered a snapshot view of resilient coping in carers. There is a lack of literature about how resilient coping may develop, be maintained, or diminished throughout the caring trajectory. Prospective longitudinal studies, following carers from the person with dementia's diagnosis through to providing end-of- life care and beyond, could address the gap in the understanding of  the resilience process in caring and when caring comes to an end (Lindert et al. 2018).

Additionally, this research has given rise to a number of unanswered questions that should be addressed in future research. For example, clarifying the mechanisms for providing social support to carers would be beneficial. This thesis examined Dementia Cafés as a social support setting, but during the recruitment phase, the diversity of approaches and interventions provided by settings which define themselves as Dementia Cafés was noted. It is not possible to assess the effectiveness of Dementia Cafés from the current evidence base as a lack of implementation fidelity (Breitenstein et al. 2010) makes comparing outcomes from different cafés difficult.

The literature identifies that resilience is a modifiable phenomenon (Mukherjee and Kumar, 2017); however, a systematic review found little evidence of the efficacy of resilience interventions in family carers (Petriwskyj et al. 2016). The review was hampered by a lack of studies, inconsistent definitions and approaches to building resilience. Identifying how and when resilient coping interventions should be delivered is an important research question, one not currently adequately answered. The design of future programmes should build on the carer-driven findings of this thesis, essentially focusing on carer definitions, strategies, and priorities for building resilience.

Mechanisms of intervention delivery should also be considered. The findings in this thesis have highlighted the value of online platforms for accessing social support. Research comparing the efficacy and acceptability of different methods of delivery of resilience-focused interventions would be beneficial. This thesis presents the first use of the BRCS in a group of carers of people with dementia. When the results of the BRCS were compared to carers' own descriptions of their level of resilience, some discrepancies were noted. This highlights the value of the co-production of resilience-focused interventions to ensure that carers' priorities are included in any programme of support.

Another question raised by this research is highlighted by an inconsistency between the qualitative and quantitative findings. Carer employment status has a non-statistically significant relationship with resilient coping (quantitative finding) but working and recently retired carers described the protective role that an occupation outside the home provided (qualitative findings). Employment provided time away from caring, a sense of purpose, social interaction, and financial support. The role that volunteering or paid employment may play in supporting carer resilience and wellbeing is an area worthy of further research. Identifying effective strategies to support carers to enter, remain in or return to work is also a research priority (National Institute for Health and Care Excellence (NICE), 2020).

Finally, in this thesis, discrepancies in carers’ perceptions of professional assessments of their resilience and the carers’ own assessments of their resilience have been noted. It is necessary to consider which competencies and skills health and social care staff need to possess in order to be able to effectively support carers to identify their own needs, preferences and feelings of resilience. This information could be used to inform a robust risk assessment and subsequent care and support plan.

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# 12 APPENDICES

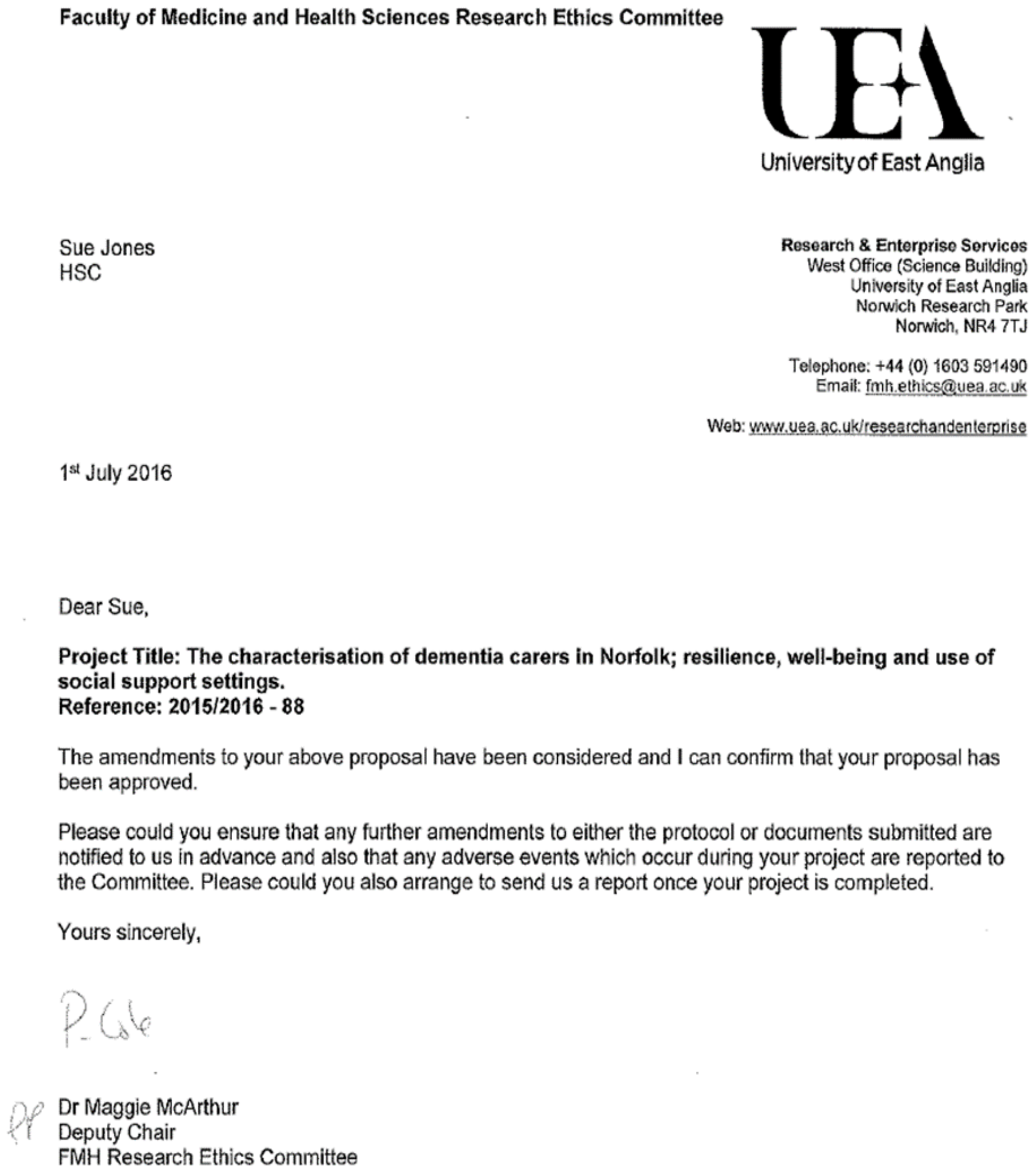
## 12.1 Personal and professional development

| Module Code | Title | Year | Credits |
|---|---|---|---|
| **MED-M51E** | Introduction to research methods | 2015/6 | 2.5 |
| **FMH1RA8Y** | Advanced research training in qualitative methods: qualitative interviewing (2 days) | 2015/6 | 2 |
| **FMH2RA6Y** | Using information skills at UEA. Endnote | 2015/6 | 0.5 |
| **FMH2RB2Y** | Introduction to ethics in health research | 2015/6 | 1 |
| **FMH2RCEY** | Mixed research methods | 2015/6 | 0.5 |
| **FMH2RD1Y** | Improving your use of Word | 2015/6 | 0.5 |
| **FMH2RD3Y** | Improving your use of Microsoft Excel | 2015/6 | 0.5 |
| **FMH2RD9Y** | Practical statistics using SPSS | 2015/6 | 1.25 |
| **FMH2RF3Y** | Introduction to academic writing in English (part 1) | 2015/6 | 0.5 |
| **FMH2RF4Y** | Plagiarism, collusion and referencing | 2015/6 | 0.5 |
| **FMH2RF5Y** | Critical thinking | 2015/6 | 0.5 |
| **FMH2RF6Y** | Presentation skills | 2015/6 | 0.5 |
| **FMH3RA3Y** | Having an impact at conference | 2015/6 | 0.5 |
|  | The faculty of medicine and health sciences student conference | 2015/6 | 1 |
| **FMH3RA5Y** | Conference: poster presentation | 2015/6 | 2 |
| **FMH3RD1Y** | How to write a thesis | 2015/6 | 0.5 |

|  |  |  |  |
|---|---|---|---|
| **FMH4RC6Y** | Managing the supervisor/supervisee relationship | 2015/6 | 0.5 |
| **FMH4RC9Y** | How to write an effective research proposal. | 2015/6 | 0.5 |
| **FMH6RC2Y** | An introduction to consultancy | 2015/6 | 0.5 |
| **FMH7RB2Y** | Patient and public involvement | 2015/6 | 0.5 |
| **FMH7RB4Y** | Taking academia into the classroom | 2015/6 | 0.5 |
| **FMH7RB6Y** | Preparing for probation review | 2015/6 | 0.5 |
| **FMHTR22Y** | FMH PGR induction | 2015/6 | 3 |
| **FMH0RA1Y** | Experiential learning: general activities (0.5) | 2016/7 | 0.5 |
| **FMH0RA4Y** | Experiential learning: general activities (2.0) | 2016/7 | 2 |
| **FMH2RD9Y** | Practical statistics using SPSS | 2016/7 | 2.5 |
| **FMH3RA4Y** | The Faculty of Medicine and Health Sciences Student Conference Poster presentation | 2016/7 | 0.5 |
| **FMH4RC3Y** | Phenomenological approaches to research | 2016/7 | 0.5 |
| **CCETRD3Y** | An introduction to NVivo | 2017/8 | 1 |
| **FMH0RA2Y** | Experiential learning: general activities (1.0) | 2017/8 | 0.5 |
| **FMH0RA4Y** | Experiential learning: general activities (2.0) | 2017/8 | 2 |
| **FMH1RA9Y** | Training in qualitative methods: Qualitative analysis and interpretation (Two days) | 2017/8 | 1 |
| **FMH3RA4Y** | The Faculty of Medicine and Health Sciences Student Conference (Oral presentation) | 2017/8 | 2 |

| | | | |
|---|---|---|---|
| **FMH3RD1Y** | How to write a thesis | 2017/8 | 0.5 |
| **FMH3RD2Y** | Preparing for your viva (final year students only) | 2017/8 | 0.5 |
| **FMH4RA1Y** | How to write for publication: Qualitative | 2017/8 | 0.5 |

## 12.2 Ethical approval: Quantitative studies.



**Faculty of Medicine and Health Sciences Research Ethics Committee**

University of East Anglia

Sue Jones
HSC

**Research & Enterprise Services**
West Office (Science Building)
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone: +44 (0) 1603 591490
Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

1st July 2016

Dear Sue,

**Project Title: The characterisation of dementia carers in Norfolk; resilience, well-being and use of social support settings.**
**Reference: 2015/2016 - 88**

The amendments to your above proposal have been considered and I can confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

P. Cole

pp Dr Maggie McArthur
Deputy Chair
FMH Research Ethics Committee

## 12.3 Consent form (Phase one)

Consent Form Dementia Carers: Resilience, wellbeing and social support v2 January 2017

Initial boxes

1. I have read and understood the participant information sheet dated January 2017. I have had the opportunity to ask questions about and discuss the contents of the participant information. ☐
2. I understand that I may not be included in the study and I will be informed if I have been included or not. ☐
3. I understand that I am free to withdraw from the study at any time without having to give a reason. ☐

Participant Signature Name Date

Signature of person seeking consent Name Date

Thank you for agreeing to take part in this research

## 12.4 Participant information sheet (Phase one)

Dementia Carers: Resilience, Wellbeing and Social Support v2 January 2017

You are being invited to take part in a research study. To help you consider whether or not to take part, please take time to read the following information carefully. If you would prefer, a member of the research team can read it through with you. Please ask if there is anything that is not clear or if you would like more information.

Background and purpose of this study

There are a variety of social support settings and groups for people with dementia and their families across the UK. Settings such as dementia cafés provide an opportunity for people with dementia and their friends and family to meet regularly in an informal social space. The cafés aim to encourage open conversations about diagnosis and its consequences. They provide support and information, giving people with dementia and their carer a place to talk to others, develop friendships and share experiences. The purpose of the research is to understand how supporting someone living with dementia affects people's resilience and wellbeing and whether attending a café or using other social support settings has an impact on this, so we are looking to recruit two groups of people: those who are able to attend a café and those who do not and we will compare the results from each group.

What does it involve?

You have been asked to take part in this study as you have experience of supporting a friend or family member with dementia. If you agree to take part you will be asked to complete a survey which asks questions about how dementia affects the person you look after and how being a carer affects your daily life. If you attend a dementia café or other support group you will be asked about the activities you take part in there. The survey takes about 30 minutes to complete. You can choose to complete it at home and post it back to us; alternatively it can be completed over the telephone at a time convenient to you. Please feel free to discuss this study with your relative if you would like to, as some of the questions relate to their wellbeing.

Will my information be kept confidential?

Yes. All information you give such as names and locations will remain completely confidential. No information that can lead to anyone being identified will be used in any report or publication that this study produces. All anonymised data will be stored on a password protected computer, in a locked office at the University of East Anglia. Data will be kept for ten years. If the researcher has concerns about your safety, that of the person you care for or others, she will discuss this with you and make any appropriate referrals to support services who may be able to help you.

### Do I have to take part?

No. It is up to you, your participation in this study does not affect your attendance at a dementia café or use of other services in any way. It will not have any negative effect on your role as a carer.

Taking part is entirely voluntary. If you decide to take part in this study you can withdraw at any time, without giving a reason. If you change your mind after you have completed the survey please contact us and we will remove it from our records and either destroy it or send it back to you if you prefer. You do not need to send back the survey if you choose not to complete it.

### What if something goes wrong?

This research is designed to minimise any risks. No medicine or active treatments are involved in this study. In the event of a problem occurring you can talk to the researcher who will try to resolve any difficulties. Alternatively please contact the project supervisor, their contact details are given at the end of this information sheet. Some people can find completing questionnaires about these issues upsetting. Contact details for the Alzheimer’s Society and Dementia UK are given below and at the end of the survey; both charities offer support, information and advice for people with dementia, their friends and family.

### Ethical approval for the study

This study has been reviewed and approved by the Faculty of Medicine and Health Science Research Ethics Committee at the University of East Anglia.

### What do I do next?

If you would like more information, or wish to take part in this study please contact **Sue Jones** at the address below. If you would like a summary of the findings at the end of the study please let the researcher know and you can be provided with a copy once the study is over. Thank you for taking the time to read this information sheet.

| Researcher Contact details | Project Supervisor Contact Details | Sources of Support |
|---|---|---|
| Sue Jones<br>University of East Anglia<br>Rm 0.07 Edith Cavell Building<br>Norwich Research park<br>NR4 7TJ<br>Tel: 01603 597065<br>Email:**sue.jones@uea.ac.uk** | Professor Eneida Mioshi<br>University of East Anglia<br>Rm 1.07 Queen's Building<br>Norwich Research park<br>NR4 7TJ<br>Tel: 01603 593300<br>Email: e.mioshi@uea.ac.uk | The Alzheimer's Society<br>Website: www.alzheimers.org.uk<br>Helpline: 0300 222 1122<br>Email: enquiries@alzheimers.org.uk<br>Dementia UK Helpline<br>Call 0800 888 6678 to speak to an Admiral Nurse<br>Website: www.dementiauk.org |

## 12.5 Letter to participants,

This letter was sent once consent to contact has been gained by partner organisations. The wording was slightly amended for email contacts.

Sue Jones

University of East Anglia

Edith Cavell Building Rm 1.27

School of Health Sciences

Norwich NR4 7TJ

Email: sue.jones@uea.ac.uk

Tel: 07827824640

Date

Dear

Re: Dementia carer’s resilience, wellbeing and social support

Thank you for your interest in the above research study. We are looking to recruit people who are caring for a relative with dementia. I have enclosed our participant information sheet to tell you more about what is involved. I will call you next week to discuss the study and see if you are interested in taking part. Alternatively please do not hesitate to contact me on the above number if you have any queries.

Kind regards

Sue Jones

Research nurse / PhD Student

Version 1 May 2016

## 12.6 Telephone transcripts

These transcripts formed the basis of conversations once potential participants had given consent to contact to partner organisations:

Call 1

Hello, my name is Sue Jones. I am working with (Insert partner organisation who gained consent to contact). I am conducting research on the experiences of people who care for relatives with dementia and I am calling you as you expressed an interest in this study.

Participation in this research involves completing a survey about how dementia affects the person you care for and how being a carer affects your daily life. If you attend a dementia café or other support group you will be asked about the activities you take part in there.

The survey takes about 35 minutes to complete although it does not need to be completed in one go. I can post it out to you or we can complete it over the telephone. Alternatively you can come to (insert partner organisation's venue) and we can complete it face to face.

Do you have questions about the research?

May I send you out the information sheet which gives you more details about the study?

Thank you for your time

Follow-up call: seven days later

Hello, my name is Sue Jones, we spoke last week about my dementia care and resilience study. Did you receive the information sheet?

Did you have any queries about the research?

We ask all participants who take part in research for their consent to use the information they give us. You can withdraw this consent at any time and we will not use the answers you gave in the survey if you do not wish us to.

Would you like to take part in this study?

If participant declines: Thank you for your time

If participant agrees: Would you like me to post the survey out to you? If it is easier I can complete it over the telephone or meet you at (insert partner organisations venue) at a time that suits you.

Arrange as per participant’s preference.

Thank you

Version 2.1 May 2016

## 12.7 Survey pack

Dementia carers: resilience, wellbeing and social support

Thank you for agreeing to take part in this survey. We will be asking about your experiences of caring for a friend or relative with dementia.

The survey should take about 35 minutes to complete, please complete it at your own pace, it does not need to be done all in one go. Some parts may appear not to apply to you or be repetitive. It does not matter if lots of your answers are the same for different questions but please answer all the questions as we need to collect the same information from everyone to get a clear understanding of the different needs and experiences people may have. The questionnaires used come from other international studies and describe a wide range of experiences, not all people will experience or should expect to experience all the difficulties or symptoms described.

Your personal details and answers to this survey will be kept confidential and no one outside the research team will have access to your survey. Information used to write the final report will be anonymised so no individual can be identified.

If you have any questions about the survey, please do not hesitate to contact me on 07827824640 or sue.jones@uea.ac.uk

Please return the survey in the pre-paid envelope provided.

Thank you in advance for your participation.

Sue Jones

Research Nurse / PhD Student

## QUESTIONS ABOUT YOU

Gender: ☐ Male ☐ Female

Age 18-29 ☐ 30-49 ☐ 50-69☐ 70-79 ☐ 80+ ☐

Your relationship to the person with dementia: ________________________________

## YOUR EDUCATION AND WORK HISTORY

1. Your highest level of education: ☐ Primary school

☐ Secondary school: O'level/GCSE

☐ Secondary school: A' level

☐ Vocational Diploma // certificate // apprenticeship

☐ Bachelor's degree

☐ Master's degree or higher

2. Your main occupation at present or in the past: __________________________________________

3. Your current work status: ☐ Part-time/casual

☐ Full-time

☐ Not currently working

☐ Retired (age at retirement: _______)

## YOUR ROLE AS CARER

1. The type of care you provide: ☐ Main carer

☐ Secondary carer

☐ Joint carer

2. The number of hours you spend ☐ 0-2 hours / week ☐ 3-10 hours / week

caring in a week: ☐ 11-20 hours / week ☐ 21-40 hours / week

☐ 41-80 hours / week ☐ 81 or more hours/ week

3. Do other family members ☐ No

help with care? ☐ Yes ______________________________________

4. How many hours in a week do they ☐ 0-2 hours / week

they help care? ☐ 3-10 hours / week

☐ 11-20 hours / week

☐ 21-40 hours / week

☐ 41-80 hours / week

☐ 81 or more hours/ week

5. Have you undertaken any training for ☐ No

carers of people with dementia? ☐ Yes: course provided by Alzheimer's Society/Age UK/other

☐ Yes: online learning (e.g. MOOC)

☐ Yes: personal study

6. Are you a member of any carer ☐ No

support groups? ☐ Yes Please give details in the table on page 4

## The following questions are about the person with dementia

Gender: ☐ Male ☐ Female

Age 18-29 ☐ 30-49 ☐ 50-69☐ 70-79 ☐ 80+ ☐

Where do they live?

☐ In their own home and alone

☐ In their own home with family

☐ Sheltered accommodation (warden on site)

☐ Sheltered accommodation (warden off site)

☐ Very sheltered/extra care accommodation

☐ Care home

Type of dementia (if known) ________________________________________________

Approximate date (year) of diagnosis (if known) __________________________________

The following questions are about the community services you or the person you care for use.

| Service | You (Please tick) | Person with dementia (Please tick) | How often do you use this service? e.g. monthly, weekly, daily |
|---|---|---|---|
| Dementia Café / Pabulum Group | | | |
| Please tell us about the activities on offer at the café / group;<br>Separate sessions for carer ☐<br>Hot meal ☐<br>Art / craft activities ☐<br>Reminiscence ☐<br>Music / dance / exercise ☐<br>Quiz ☐<br>Cards / dominoes / games ☐<br>Other, please describe | | | |
| Carers support group | | | |
| Day centre | | | |
| Cognitive stimulation therapy (CST) group | | | |
| Community mental health team | | | |
| Occupational therapy | | | |
| Physiotherapy | | | |
| Psychology | | | |
| Admiral nurse | | | |
| Dementia advisor/support worker | | | |
| Social worker | | | |
| Personal home care | | | |

| | | | |
|---|---|---|---|
| Domestic home care (cleaner) | | | |
| Sitting service / befriending | | | |
| Other (please specify) | | | |

Part two: Questions about you.

This questionnaire asks about you satisfaction with life at the moment. The following questions ask how satisfied you feel on a scale from zero to 10. Zero means you feel completely dissatisfied, 10 means you feel completely satisfied. The middle of the scale is five which means you feel neutral, neither satisfied nor dissatisfied.

Part 1:

1.

Very unsatisfied Neutral Very satisfied

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Thinking about your life and personal circumstances, how satisfied are you with your life as a whole? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

Part 2:

Very unsatisfied Neutral Very satisfied

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **How satisfied are you with your standard of living?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How satisfied are you with your health?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How satisfied are you with what you are achieving in life?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How satisfied are you with your personal relationship?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How satisfied are you with how safe you feel?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How satisfied are you with feeling a part of your community?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How satisfied are you with your future security?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **How satisfied are you with your spirituality or religion?** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

***Thank you. Please continue to the next page***

The following questions ask about different ways people cope. Please respond to each item by marking one box per row

| | Does not describe me at all | Does not describe me | Neutral | Describes me | Describes me very well |
|---|---|---|---|---|---|
| I look for creative ways to alter difficult situations. | 1 | 2 | 3 | 4 | 5 |
| Regardless of what happens to me, I believe I can control my reaction to it. | 1 | 2 | 3 | 4 | 5 |
| I believe that I can grow in positive ways by dealing with difficult situations. | 1 | 2 | 3 | 4 | 5 |
| I actively look for ways to replace the losses I encounter in life. | 1 | 2 | 3 | 4 | 5 |

***Thank you. Please continue to the next page***

**Social Networks:** People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? **Please circle the number in the box that best applies to you.**

|  | Never | Rarely | Sometimes | Quite frequently | Nearly always |
|---|---|---|---|---|---|
| Emotional / Informational Support |  |  |  |  |  |
| 1. Someone you can count on to listen to when you need to talk | 0 | 1 | 2 | 3 | 4 |
| 2. Someone to give you information to help you understand a situation | 0 | 1 | 2 | 3 | 4 |
| 3. Someone to give you good advice about a crisis | 0 | 1 | 2 | 3 | 4 |
| 4. Someone to confide in or talk to about yourself or your problems | 0 | 1 | 2 | 3 | 4 |
| 5. Someone whose advice you really want | 0 | 1 | 2 | 3 | 4 |
| 6. Someone to share your most private worries and fears with | 0 | 1 | 2 | 3 | 4 |
| 7. Someone to turn to for suggestions about how to deal with a personal problem | 0 | 1 | 2 | 3 | 4 |
| 8. Someone who understands your problems | 0 | 1 | 2 | 3 | 4 |
| Tangible Support |  |  |  |  |  |
| 9. Someone to help you if you were confined to bed | 0 | 1 | 2 | 3 | 4 |
| 10. Someone to take you to the doctor if you needed it | 0 | 1 | 2 | 3 | 4 |

*Thank you. Please continue to the next page*

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| 11. Someone to prepare your meals if you were unable to do it yourself | 0 | 1 | 2 | 3 | 4 |
| 12. Someone to help with daily chores if you were sick | 0 | 1 | 2 | 3 | 4 |
| Affectionate Support |  |  |  |  |  |
| 13. Someone who shows you love and affection | 0 | 1 | 2 | 3 | 4 |
| 14. Someone to love you and make you feel wanted | 0 | 1 | 2 | 3 | 4 |
| 15. Someone who hugs you | 0 | 1 | 2 | 3 | 4 |
| Positive Social Interaction |  |  |  |  |  |
| 16. Someone to have a good time with | 0 | 1 | 2 | 3 | 4 |
| 17. Someone to get together with for relaxation | 0 | 1 | 2 | 3 | 4 |
| 18. Someone to do something enjoyable with | 0 | 1 | 2 | 3 | 4 |
| Additional item |  |  |  |  |  |
| 19. Someone to do things with to help you take your mind off things. | 0 | 1 | 2 | 3 | 4 |

***Thank you. Please continue to the next page***

The following questions ask about your feelings about caring. Please indicate how often you experience the feelings listed by **circling the number in the box** that best corresponds to the frequency of these feelings. Don't worry if some questions appear not to apply to you. We have to ask the same questions of everybody.

| | | Never | Rarely | Sometimes | Quite frequently | Nearly always |
|---|---|---|---|---|---|---|
| 1 | Do you feel that because of the time you spend with your relative that you do not have enough time for yourself? | 0 | 1 | 2 | 3 | 4 |
| 2 | Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)? | 0 | 1 | 2 | 3 | 4 |
| 3 | Do you feel angry when you are around the relative? | 0 | 1 | 2 | 3 | 4 |
| 4 | Do you feel that your relative currently affects your relationship with family member or friends in a negative way? | 0 | 1 | 2 | 3 | 4 |
| 5 | Do you feel strained when you are around your relative? | 0 | 1 | 2 | 3 | 4 |
| 6 | Do you feel that your health has suffered because of your involvement with your relative? | 0 | 1 | 2 | 3 | 4 |
| 7 | Do you feel that you do not have much privacy as you would like because of your relative? | 0 | 1 | 2 | 3 | 4 |
| 8 | Do you feel that your social life has suffered because you are caring for your relative? | 0 | 1 | 2 | 3 | 4 |
| 9 | Do you feel that you have lost control of your life since your relative's illness? | 0 | 1 | 2 | 3 | 4 |
| 10 | Do you feel uncertain about what to do about your relative? | 0 | 1 | 2 | 3 | 4 |

***Thank you. Please continue to the next page***

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| 11 | Do you feel you should be doing more for your relative? | 0 | 1 | 2 | 3 | 4 |
| 12 | Do you feel you could do a better job in caring for your relative? | 0 | 1 | 2 | 3 | 4 |

***Thank you. Please continue to the next page***

The following questions are about your mood. For each statement below please circle the number that best describes how you have been feeling in the last week.

| | | **Did not apply to me at all** | **Applied to me sometimes** | **Applied to me a good part of the time** | **Applied to me most of the time** |
|---|---|---|---|---|---|
| **1** | I found it hard to wind down | 0 | 1 | 2 | 3 |
| **2** | I was aware of the dryness of my mouth | 0 | 1 | 2 | 3 |
| **3** | I couldn't seem to experience any positive feelings at all | 0 | 1 | 2 | 3 |
| **4** | I experienced breathing difficulty<br>(e.g. excessively rapid breathing, breathlessness in the absence of physical exertion) | 0 | 1 | 2 | 3 |
| **5** | I found it difficult to work up the initiative to do things | 0 | 1 | 2 | 3 |
| **6** | I tended to over react to situations | 0 | 1 | 2 | 3 |
| **7** | I experienced trembling (e.g. in my hands) | 0 | 1 | 2 | 3 |
| **8** | I felt I was using a lot of nervous energy | 0 | 1 | 2 | 3 |
| **9** | I was worried about situations in which I might panic and make a fool of myself | 0 | 1 | 2 | 3 |
| **10** | I felt I had nothing to look forward to | 0 | 1 | 2 | 3 |
| **11** | I found myself getting agitated | 0 | 1 | 2 | 3 |
| **12** | I found it difficult to relax | 0 | 1 | 2 | 3 |

*Thank you. Please continue to the next page*

|  |  | **Did not apply to me at all** | **Applied to me sometimes** | **Applied to me a good part of the time** | **Applied to me most of the time** |
|---|---|---|---|---|---|
| **13** | I felt downhearted and blue | 0 | 1 | 2 | 3 |
| **14** | I was intolerant of anything that kept me from getting on with what I was doing | 0 | 1 | 2 | 3 |
| **15** | I felt I was close to panic | 0 | 1 | 2 | 3 |
| **16** | I was unable to become enthusiastic about anything | 0 | 1 | 2 | 3 |
| **17** | I felt I wasn't worth much as a person | 0 | 1 | 2 | 3 |
| **18** | I felt that I was rather touchy | 0 | 1 | 2 | 3 |
| **19** | I was aware of the action of my heart in the absence of physical exertion (e.g. Sense of heart rate increase, heart missing a beat) | 0 | 1 | 2 | 3 |
| **20** | I felt scared without any good reason | 0 | 1 | 2 | 3 |
| **21** | I felt that life was meaningless | 0 | 1 | 2 | 3 |

***Thank you. Please continue to the next page***

## Part three: Questionnaires about the person with dementia

We would like to ask you a number of questions about changes in the person's behaviour that you may have noticed in the last month. Please read each item carefully. Then, circle the number under the heading "Frequency" that best describes how often the behaviour happens. Then, circle the letter under "How much did it bother you?" that best describes your disturbance by this behaviour. Some of the everyday skills may not apply, if for instance the person with dementia has never done the shopping. Please enter N/A (not applicable). All questions apply to **changes** in the person's behaviour from how they were **before the illness until now**.

| | | |
|---|---|---|
| | 0 = Never<br>1 = rarely (a couple of times a month)<br>2 = sometimes (a couple of times a week)<br>3 = Frequently (daily)<br>4 = Nearly always (constantly) | a = Not at all<br>b = a little<br>c = moderately<br>d= very much<br>e = extremely |
| Memory and Orientation | Frequency | How much did it bother you? |
| Has poor day-to-day memory (e.g. about conversations, trips etc.) | 0 1 2 3 4 | a b c d e |
| Asks the same questions over and over again | 0 1 2 3 4 | a b c d e |
| Loses or misplaces things | 0 1 2 3 4 | a b c d e |
| Forgets the names of familiar people | 0 1 2 3 4 | a b c d e |
| Forgets the names of objects and things | 0 1 2 3 4 | a b c d e |
| Shows poor concentration when reading or watching television | 0 1 2 3 4 | a b c d e |
| Forgets what day it is | 0 1 2 3 4 | a b c d e |
| Becomes confused or muddled in unusual surroundings | 0 1 2 3 4 | a b c d e |

*Thank you. Please continue to the next page*

| | 0 = Never<br>1 = rarely (a couple of times a month)<br>2 = sometimes (a couple of times a week)<br>3 = Frequently (daily)<br>4 = Nearly always (constantly) | a = Not at all<br>b = a little<br>c = moderately<br>d= very much<br>e = extremely |
|---|---|---|
| Everyday Skills | | |
| Has difficulties using electrical appliances (e.g. TV, radio, cooker, washing machine) | 0 1 2 3 4 | a b c d e |
| Has difficulties writing (letters, Christmas cards, lists etc.) | 0 1 2 3 4 | a b c d e |
| Has difficulties using the telephone | 0 1 2 3 4 | a b c d e |
| Has difficulties making a hot drink (e.g. tea/coffee) | 0 1 2 3 4 | a b c d e |
| Has problems handling money or paying bills | 0 1 2 3 4 | a b c d e |
| Self-Care | | |
| Has difficulties grooming self (e.g. shaving or putting on make-up) | 0 1 2 3 4 | a b c d e |
| Has difficulties dressing self | 0 1 2 3 4 | a b c d e |
| Has problems feeding self without assistance | 0 1 2 3 4 | a b c d e |
| Has problems bathing or showering self | 0 1 2 3 4 | a b c d e |
| Behaviour | | |
| Finds humour or laughs at things others do not find funny | 0 1 2 3 4 | a b c d e |
| Has temper outbursts | 0 1 2 3 4 | a b c d e |

***Thank you. Please continue to the next page***

| | | |
|---|---|---|
| | 0 = Never<br>1 = rarely (a couple of times a month)<br>2 = sometimes (a couple of times a week)<br>3 = Frequently (daily)<br>4 = Nearly always (constantly) | a = Not at all<br>b = a little<br>c = moderately<br>d= very much<br>e = extremely |
| Shows socially embarrassing behaviour | 0 1 2 3 4 | a b c d e |
| Makes tactless or suggestive remarks | 0 1 2 3 4 | a b c d e |
| Acts impulsively without thinking | 0 1 2 3 4 | a b c d e |
| Mood | | |
| Cries | 0 1 2 3 4 | a b c d e |
| Appears sad or depressed | 0 1 2 3 4 | a b c d e |
| Is very restless or agitated | 0 1 2 3 4 | a b c d e |
| Is very irritable | 0 1 2 3 4 | a b c d e |
| Beliefs | | |
| Sees things that are not really there (visual hallucinations) | 0 1 2 3 4 | a b c d e |
| Hears voices that are not really there (auditory hallucinations) | 0 1 2 3 4 | a b c d e |
| Has odd or bizarre ideas that cannot be true | 0 1 2 3 4 | a b c d e |
| Eating Habits | | |
| Prefers sweet foods more than before | 0 1 2 3 4 | a b c d e |
| Wants to eat the same foods repeatedly | 0 1 2 3 4 | a b c d e |
| Her/his appetite is greater, s/he eats more than before | 0 1 2 3 4 | a b c d e |
| | | |

***Thank you. Please continue to the next page***

| | | |
|---|---|---|
| | 0 = Never<br>1 = rarely (a couple of times a month)<br>2 = sometimes (a couple of times a week)<br>3 = Frequently (daily)<br>4 = Nearly always (constantly) | a = Not at all<br>b = a little<br>c = moderately<br>d= very much<br>e = extremely |
| Sleep | | |
| Sleep is disturbed at night | 0 1 2 3 4 | a b c d e |
| Sleeps more by day than before (cat naps etc.) | 0 1 2 3 4 | a b c d e |
| Routines | | |
| Is rigid and fixed in her/his ideas and opinions | 0 1 2 3 4 | a b c d e |
| Develops routines from which s/he cannot easily be discouraged e.g. wanting to eat or go for walks at fixed times | 0 1 2 3 4 | a b c d e |
| Clock watches or appears pre-occupied with time | 0 1 2 3 4 | a b c d e |
| Repeatedly uses the same expression or catch phrase | 0 1 2 3 4 | a b c d e |
| Motivation | | |
| Shows less enthusiasm for his or her usual interests | 0 1 2 3 4 | a b c d e |
| Shows little interest in doing new things | 0 1 2 3 4 | a b c d e |
| Fails to maintain motivation to keep in contact with friends or family | 0 1 2 3 4 | a b c d e |
| Appears indifferent to the worries and concerns of family members | 0 1 2 3 4 | a b c d e |

***Thank you. Please continue to the next page***

Activities of Daily Living

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties. For each activity (No. 1 - 20), statements a - e refer to a different level of ability.

Thinking of the last 2 weeks, circle the letter that represents your relative’s/friend’s AVERAGE ability for each activity. Circle e) Not applicable if your relative / friend never did that activity when they were well.

1. PREPARING FOOD

a) Selects and prepares food as required

b) Able to prepare food if ingredients set out

c) Can prepare food if prompted step by step

d) Unable to prepare food even with prompting and supervision

e) Not applicable

2. EATING

a) Eats appropriately using correct cutlery

b) Eats appropriately if food made manageable and /or uses spoon

c) Uses fingers to eat food

d) Needs to be fed

e) Not applicable

3. PREPARING A DRINK

a) Selects and prepares drinks as required

b) Can prepare drinks if ingredients left available

c) Can prepare drinks if prompted step by step

d) Unable to make a drink even with prompting and supervision

e) Not applicable

4. DRINKING

a) Drinks appropriately

b) Drinks appropriately with aids, beaker/straw etc.

c) Does not drink appropriately even with aids but attempts to

d) Has to have drinks administered (fed)

e) Not applicable

5. DRESSING

a) Selects appropriate clothing and dresses self

b) Puts clothes on in wrong order and/or back to front and/or dirty clothing

c) Unable to dress self but moves limbs to assist

d) Unable to assist and requires total dressing

e) Not applicable

*Thank you. Please continue to the next page*

6. HYGIENE

a) Washes regularly and independently

b) Can wash self if given soap, flannel, towel, etc.

c) Can wash self if prompted and supervised

d) Unable to wash self and needs full assistance

e) Not applicable

7. TEETH

a) Cleans own teeth/dentures regularly and independently

b) Cleans teeth/dentures if given appropriate items

c) Requires some assistance, toothpaste on brush, brush to mouth etc.

d) Full assistance given

e) Not applicable

8. BATH/SHOWER

a) Bathes regularly and independently

b) Needs bath to be drawn/shower turned on but washes independently

c) Needs supervision and prompting to wash

d) Totally dependent, needs full assistance

e) Not applicable

9. TOILET/COMMODE

a) Uses toilet appropriately when required

b) Needs to be taken to the toilet and given assistance

c) Incontinent of urine or faeces

d) Incontinent of urine and faeces

e) Not applicable

10. TRANSFERS

a) Can get in/out of chair unaided

b) Can get into a chair but needs help to get out

c) Needs help getting in and out of a chair

d) Totally dependent on being put into and lifted from chair

e) Not applicable

11. MOBILITY

a) Walks independently

b) Walks with assistance i.e. furniture, arm for support

c) Uses aids to mobilise i.e. frame, sticks etc.

d) Unable to walk

e) Not applicable

*Thank you. Please continue to the next page*

12. ORIENTATION -TIME

a) Fully orientated to time/day/date etc.

b) Unaware of time/day etc. but seems unconcerned

c) Repeatedly asks the time/day/date

d) Mixes up night and day

e) Not applicable

13. ORIENTATION - SPACE

a) Fully orientated to surroundings

b) Orientated to familiar surroundings only

c) Gets lost in home, needs reminding where bathroom is, etc.

d) Does not recognise home as own and attempts to leave

e) Not applicable

14. COMMUNICATION

a) Able to hold appropriate conversation

b) Shows understanding and attempts to respond verbally with gestures

c) Can make self-understood but difficulty understanding others

d) Does not respond to, or communicate with others

e) Not applicable

15. TELEPHONE

a) Uses telephone appropriately, including obtaining correct number

b) Uses telephone if number given verbally/visually or pre-dialled

c) Answers telephone but does not make calls

d) Unable/unwilling to use telephone at all

e) Not applicable

16. HOUSEWORK /GARDENING

a) Able to do housework/gardening to previous standard

b) Able to do housework/gardening but not to previous standard

c) Limited participation with a lot of supervision

d) Unwilling/unable to participate in previous activities.

e) Not applicable

17. SHOPPING

a) Shops to previous standard

b) Only able to shop for 1 or 2 items with or without a list

c) Unable to shop alone, but participates when accompanied

d) Unable to participate in shopping even when accompanied

e) Not applicable

***Thank you. Please continue to the next page***

18. FINANCES

a) Responsible for own finances at previous level

b) Unable to write a cheque. Can sign name & recognises money values

c) Can sign name but unable to recognise money values

d) Unable to sign name or recognise money values

e) Not applicable

19. GAMES/HOBBIES

a) Participates in pastimes/activities to previous standard

b) Participates but needs instruction/supervision

c) Reluctant to join in, very slow needs coaxing

d) No longer able or willing to join in

e) Not applicable

20. TRANSPORT

a) Able to drive, cycle or use public transport independently

b) Unable to drive but uses public transport or bike etc.

c) Unable to use public transport alone

d) Unable/unwilling to use transport even when accompanied

e) Not applicable

Thank you. You have completed the survey

*Thank you. Please continue to the next page*

## Sources of Support and Information.

### *Dementia UK Helpline*

The helpline is staffed by Admiral Nurses who can give specialist practical and emotional support. Please call **0800 888 6678** from 9:15am to 4.45pm Monday to Friday and also from 6pm to 9pm on Wednesday and Thursday evenings.

### *The Alzheimer's Society*

The Alzheimer's Society offers information, advice and support for people with dementia and their families through its resources and local groups

Website: www.alzheimers.org.uk

Helpline: **0300 222 1122**
Email: enquiries@alzheimers.org.uk

If you would be interested in being contacted about future research taking place at the University of East Anglia please provide contact details below.

Name: ______________________________________________

Telephone number: ____________________________

Email address: _______________________________________

Thank you for your time.

Please post your completed survey back to us in the pre-paid envelope

## 12.8 Ethical approval: Qualitative studies

**Faculty of Medicine and Health Sciences Research Ethics Committee**

University of East Anglia

**Research & Enterprise Services**
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Telephone: +44 (0) 1603 591490
Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

Sue Jones
HSC

13th July 2017

Dear Sue,

**Project title: Exploring opportunities for carer resilience through social support (CARIS)**
**Reference: 2016/2017 - 86**

The amendments to your above proposal have been considered and I can confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

Professor M J Wilkinson
Chair
FMH Research Ethics Committee

**cc. Eneida Mioshi**

## 12.9 Consent form (Phase two)

Exploring opportunities for carer resilience through social support.)

Participant Consent Form. (July 2017v1)

Please initial each box

1. I confirm that I have read and understand the information sheet (July 2017 v1) ☐

for the above study and have had the opportunity to ask questions.

2. I understand that my participation in the interview is voluntary and that I am free to withdraw from the study at any time, without having to give a reason. If I choose to withdraw after the interview it will be removed from the study records. ☐

3. I understand that the interview will be recorded on a digital recorder and written out word for word later. I give permission for doing this. ☐

4. I consent to the storage including electronic, of personal information for the purposes of this study. I understand that any information that could identify me will be kept strictly confidential and that no personal information will be included in the study report or other publication. ☐

5. I understand that what I say during the interview is confidential under the Data Protection Act. However, if the interviewer believes that there is a significant risk to me or someone else, they may need to pass this information on. If this happens, they will discuss it with me first before anyone else is told. ☐

6. I agree to take part in an interview for the above study. ☐

Name of the participant (Print) Date

Participant's signature

Name of person taking consent (Print) Sue Jones Date

Researcher Signature

## 12.10 Participant information sheet (Phase two)

### Exploring opportunities for carer resilience through social support (July 2017 v1)

You are invited to take part in a research study. To help you consider whether to take part, please take time to read the following information carefully. A member of the research team can read it through with you if you prefer. Please ask if there is anything that is not clear or if you would like more information.

### Background and purpose of this study

Some people find caring for a friend or relative with dementia can be stressful. There are often unexpected challenges. Being resilient and having social support are known to help our physical and mental wellbeing. However, the practical demands of being a carer for someone with dementia may change how resilient we feel. Our aim is to understand more about resilience in people who support a person with dementia. We are interested in the challenges they may face and the ways in which they overcome these challenges.

### Why have I been invited to take part?

You are being asked to take part in this study as you have experience of supporting a friend or family member with dementia.

### What will happen if I take part?

If you agree to take part in the study you will be asked to participate in an interview. The interview will be arranged for a time, date and place that are convenient for you. The interview is likely to last about an hour. You will be asked if you are happy for the interview to be recorded, so that we can write up what was said and think about it carefully afterwards

In the interview there are no right and wrong answers to any questions; we are just interested in hearing your experiences. We are interested in your experiences of support from family, friends, neighbours and the wider community.

Will my information be kept confidential?

Yes. All information you give such as names and locations will remain completely confidential. We may use written quotations from the interview in presentations, written articles or teaching. If we do we will take care not to use any words that could lead to anyone identifying you. All data such as the written out words from an interview will be anonymised. Data is stored on a password protected computer, in a locked office at the University of East Anglia. Data is kept for ten years. If the researcher has concerns about your safety, that of the person you care for or others, she will discuss this with you and may need to pass on your information and make a safeguarding referral to support services who may be able to help you.

Do I have to take part?

No. Taking part is entirely voluntary. If you decide to take part in this study you can withdraw at any time, without giving a reason. If you change your mind after you have completed the interview please contact us and we will remove it from our records. Taking part or not taking part will not affect your contact with any other services.

What are possible disadvantages and risks of taking part?

This research is designed to minimise any risks. No medicine or active treatments are involved in this study. Some people can find talking about these issues upsetting. If you were to become upset the interview could be stopped. The interview could be continued another time, or you could choose to withdraw from the study. In the event of a problem occurring you can talk to the researcher who will try to resolve any difficulties. Alternatively please contact the project supervisor, their contact details are given at the end of this information sheet. Contact details for the Alzheimer’s Society and Dementia UK are given below. Both charities offer support, information and advice for people with dementia, their friends and family.

Ethical approval for the study

This study has been reviewed and approved by the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of East Anglia.

What do I do next?

If you would like more information, or wish to take part in this study, please contact **Sue Jones** at the address below. If you would like a summary of the findings please let the researcher know and you can be provided with a copy once the study is over.

Thank you for taking the time to read this information sheet.

| Researcher Contact details | Project Supervisor Contact Details | Sources of Support |
|---|---|---|
| Sue Jones<br>University of East Anglia<br>Rm 0.07 Edith Cavell Building<br>Norwich Research park<br>NR4 7TJ<br>Tel: 01603597065<br>Email: sue.jones@uea.ac.uk | Professor Eneida Mioshi<br>University of East Anglia<br>Rm 1.07 Queen’s Building<br>Norwich Research park<br>NR4 7TJ<br>Tel: 01603 593300<br>Email: e.mioshi@uea.ac.uk | The Alzheimer's Society<br>Website: www.alzheimers.org.uk<br>Helpline: 0300 222 1122<br>enquiries@alzheimers.org.uk<br>Dementia UK Helpline<br>Call 0800 888 6678 to speak to an Admiral Nurse<br>Website: www.dementiauk.org |

## 12.11 Interview topic guide

### Exploring opportunities for carer resilience through social support.

The researcher will take their lead in relation to specific words and terminology from the participant. E.g. where the individual identifies as a carer, this term will be used; others may prefer the term ‘care partner’ etc. Language will be adapted to be appropriate to each participant e.g. some individuals may prefer a more formal form of address and phrasing of questions.

The broad structure of the interview is as follows:

**Introduction:** The aim of this section is to introduce myself and thank the participant for allowing me to visit them. I will describe what the interview covers, what I hope to find out and why this is important. I will say how long the interview is expected to take and ask if they are happy to proceed.

E.g. Hello, My name is Sue, I’m a Research Nurse based at the University of East Anglia. Thank you for agreeing to see me today. Today’s interview will ask about you and ________, the support you provide for him/her and the help you may get from friends, family and neighbours. The interview should take about an hour, are you happy to carry on and answer some questions today?

Part one: Questions about the context of care.

First I’d like to ask about you and ______ to find out a little more about you both and how the dementia may have changed things for you.

Questions will be asked in the most logical order dictated by the participant’s conversation/ context and will include:

- How long have you lived in __________ (town/village)
- How old are you and __________?
- Are you currently working? What type of work did you do?
- How long have you been married/living together/in a civil partnership? (if applicable)
- When was ___________ diagnosed with dementia?
- What type of dementia does _________ have?

- What sort of things do you help him/her with?
- Can you estimate how many hours a week you are caring for ___________?

Part two: Establishing the participant’s understanding of key concepts.

E.g. When you heard this study was about resilience what sprang to mind?

E.g. How would you describe a resilient person?

E.g. Can you think of someone who is resilient? What makes you think they are resilient?

- Are you a resilient person?
- Would other people describe you as resilient?

Part three: Exploring challenges and coping strategies.

This section uses the answers given in parts 1 and 2 to explore experiences. Questions and prompts will be phrased using the participant’s own words wherever possible.

E.g. Earlier you spoke about the diagnosis of _’s dementia, has this brought any particular challenges?

E.g. How has your world changed since the diagnosis?

(Consider: changing social support networks/feelings of anxiety, stress and depression)

E.g. Earlier you said resilience was ________________, is this effected by the challenges of dementia caring?

E.g. What makes you feel more/less resilient?

(Consider: PWD symptoms/attending social groups)

E.g. Do you have any specific habits/strategies that help you feel resilient?

E.g. Do you get any help to support you as a carer?

Closing:

E.g. Thank you for answering all my questions, I appreciate the time you took today. Is there anything else you think it would be helpful for me to know about the things we’ve talked about?  Would you like me to contact you when we have a summary of provisional results?

## 12.12 Sampling matrix

| | Age | Gender | | Relationship | | | Employment | | | | | Education | | | Cohabiting | Multiple caring roles | Type of dementia | PWD Dependency (Bristol) | | | Yrs since diagnosis | Carer resilience (BRCS) | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Participant | Less than 40 yrs | M | F | Spouse | Adult child | Other | FT | PT | Student | Ret | Unwaged | School | Voc | HE | Y | | | L | M | H | | L | M | H |
| Anne | | | x | x | | | | x | | | | | | x | x | | DLB/FTD | | x | x | 4 | x | | |
| Pat | | | | | | | | | | x | | | | x | x | x | other | | | x | 7 | | | x |
| Theresa | | | x | | | | | | | x | | | | x | | | Vas | | x | | 3 | x | | |
| Evelyn | | | x | x | | | | | | x | | x | | | x | | bvFTD | x | x | | 1 | x | | |
| Daniel | | x | | | x | | | | | x | | | x | | | x | AD | x | x | | | | | x |
| Bertie | | x | | | | x | | | | x | | | x | | x | | AD | | x | | 3 | | | x |
| Linda | | | x | | x | | | | | | | | x | | Dec | | Vas | | | | unk | x | | |
| Sandra | | | x | | x | | x | | | | | | x | | | | svFTD | | x | | <1 | | x | |
| Mike | | x | | x | | | | x | | | | | | x | x | | Bv/FTD | | x | | 3 | x | | |
| Tuli | | | | | | x | | x | x | | | | | x | | | Vas | | | x | 10 | | | x |
| Jean | | | x | x | | | | | | x | | x | | | x | | AD/Vas | | x | | 5 | x | | |
| Tom | | x | | x | | | | | | x | | | x | | x | | AD | | | x | 6 | | | x |
| Denise | | | x | | x | | | | | | x | x | | | x | x | AD/Vas | | x | | 5 | | x | |

Dec deceased, Ret retired, PWD person with dementia, AD Alzheimer’s disease DLB dementia with Lewy bodies, bvFTD behavioural variant fronto temporal dementia, svFTD semantic variant fronto temporal dementia, PPA primary progressive aphasia, unk unknown, BRCS – Brief Resilient Coping Scale.

## 12.13 Extract from coding framework

(H) High resilience (M) Medium resilience (L) Low resilience as per BRCS scores

| Categories | Description | Example quotes | Refined category | Interpretation | Final theme |
|---|---|---|---|---|---|
| faith | Personal spiritual beilefs, religious practice or attendance at a place of worship | My kind of self-help group is probably the church. You know for – not just for a Sunday morning – we have midweek meetings. One of our Pastors is coming round tonight to do a pastoral visit. (H) | Faith and spirituality | Support arising from personal faith or religious community | Faith and fellowship |
| peer group/ role models | availability of people in the network with similar experience | I have just actually come from having coffee with three ladies who I met at the Dementia Club – all of whom husbands have died. So they're still sort of a fairly strong support network. (L) | Social connection | 'Safe' friends who understand the context of caring | Integration |
| changing relationships with pwd/ | changing relationships with pwd/ friends/family | Our friendships are like a Venn diagram, aren't they? You have different circles for different things and they overlap in places and you don't tell everybody the same thing (L) | Loss of pre-existing networks | Segregation and demarcation | Independence |

| | | | | | |
|---|---|---|---|---|---|
| friends/ family | | | | | |
| e-friendships | maintaining friendships via social media | WhatsApp, you know the social media thing and the fact that I am quite good at staying in touch with friends, email is useful for that. I'm not a great phoner because I think phoning is intrusive. (L) I've joined the Facebook one, which is dementia, devoted to dementia carers. And you know, it's interesting because a lot of the stuff makes you feel good when you see it. (H) | Social connection | Remote communication: overcomes the challenge of geography, time etc. | Integration |

## 12.14 Extract from the data synthesis matrix

| Resilience framework | Quantitative findings | Match (Convergence) | Supported (Complementarity) | Disagreed (Dissonance) | Absent (Silence). |
|---|---|---|---|---|---|
| Individual | Socio-demographic characteristics (excluding gender) had no association with resilient coping | | | 1) Some carers believed they had grown into resilience as part of a ‘life long process’ suggesting age may be a factor.<br>2) Employment was described as a resilient coping strategy.<br>3) The challenges or benefits of maintaining the pre-existing relationship (child/spouse) were discussed as either promoting or threatening resilience. | 1) Neither residence nor education level were mentioned by carers as being related to their resilience. |

| | | | | | |
|---|---|---|---|---|---|
| | Carers reported higher depression, anxiety and stress scores than indicated in the DASS normative data | 1) Carers described physical and mental ‘exhaustion’ | | | |
| | Carers can be both resilient and distressed | | 1) Passive definitions of resilience acknowledged both distress and resilience<br>2) Appearances of coping can be deceptive. Resilience and distress can co-exist | | |
| | Resilience has a mediating effect on distress | 1) Resilience was described as a ‘buffer’ in times of stress | | | |

Qualitative findings (in blue) are cross-referenced with quantitative findings to ascertain if they matched, did not match but supported, disagreed or were absent in the qualitative data

## 12.15 Personal reflection

Extract 1 April 2016

As I'm approaching this research I am aware my own biases could affect the way I see the data, and my interpretations of the experiences carers may have. As I have worked as a nurse within the field of dementia care for 20 years and have personal experience for caring for a terminally ill family member (although not with dementia), I realise that I am undertaking this research with existing knowledge and experience. Furthermore, as a result of my literature review, which was conducted and revised over a period of three years, a variety of journal articles, research seminars and personal meetings have also contributed to my knowledge. This broad information has helped me to solidify and articulate my personal and professional experiences. The purpose of writing this section is to identify what I feel may be important before I start collecting or analysing data. This may help direct my interpretation of data and may help me be aware of any leading questions that I may ask. This is not intended to be an exhaustive list or explanation of my own knowledge or experience; it should be a recognition of the ideas that I have foremost in my mind when approaching the research, research participants and data.

The role of family:

My family works well together at times of stress, each person naturally adopting a role they are most able to effectively contribute within. When caring for a family member with MND I provided evening care, meds, tube feeds. My aunt covered weekends and housework. My brother supported his grandfather socially and emotionally, my father provided practical assistance. My father and his sister provided strong advocacy and co-ordinated services. I have worked with families who have much more complex dynamics and experience conflict at times of stress.

The role of support groups

I have facilitated many types of support group for various participants and have seen great value in the relationships and revelations that can develop within a group setting. I believe they are a valuable resource and even people who are reluctant to attend may find that it is useful for them. I have seen that people find the idea of groups very daunting and I believe they should have access to alternative individual support.

I have attended a support group during a period of ill-health and found it assisted my recovery.

### The role of the wider community

I grew up in East London, my experience is of a disparate community with clear demarcation of different religious and social groups. I work in an area of the UK that lacks the ethnic diversity of where I grew up. It is an area which is popular with retiring couples, many of whom have settled a fair distance from their families and friends from work. This has left them without a social network. Some families are successful at developing a new social network others become increasingly isolated.

### Extract 2  November 2017

### Challenges of being a nurse researcher.

When conducting this study I had been a community mental health nurse for over twenty years and a PhD candidate for two years. I was constantly alert to the different requirements of each role. I chose a methodology which enabled me to integrate both roles, interpretive description, due to its origins in nursing and focus on data collection in clinical areas for the purpose of learning more about the setting, service users and nursing practice.

The challenge for me was balancing my ingrained clinical instincts with my role as a researcher. In some areas this was very liberating; as people told me of the daily challenges they faced and I was able to listen without there being any expectation on me to ‘fix’ anything. Instead it was my responsibility to listen, interpret and integrate their story into that of the own study.

This presented a new and unexpected challenge. As a nurse it is automatic to maintain the individual’s voice and unique experience, as I need to consider only them and their situation to devise and implement a bespoke treatment plan. The study required both the individual voice and assimilation of the whole sample, and the use of a reflective diary; constantly revisiting the coding framework supported this.