# THE UNIVERSITY OF HULL

Resilience in people with dementia and their caregivers

being a Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

Lucy Kathryn Conway, BSc (Hons) Psychology

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### Acknowledgements

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Overview

This portfolio thesis consists of three parts: a systematic literature review, an empirical

paper and appendices relating to both research projects.

The first section is a systematic literature review which aimed to synthesise

research into resilience in relation to people living with dementia, caregivers and

dementia dyads to understand the factors which maintain resilience and the extent to

which a dyadic perspective is taken. Ten papers met the inclusion criteria and were

synthesised using narrative synthesis, with findings categorised into individual,

community and social resources. The findings suggest that people living with dementia

and their caregivers utilise resources in order to maintain their resilience; however,

research has failed to consider the dyadic perspective. The findings from the review are

discussed in relation to the wider context of literature, with implications for future

research discussed.

The empirical research aimed to develop a theory and understanding of shared

resilience between people with dementia and their spouses. The research aimed to

develop a definition of resilience, understand what helps couples to develop and maintain

their resilience, as well as consider the impact that resilience has on their relationship and

well-being. The research used a qualitative Constructivist Grounded Theory approach

interviewing 12 couples. Findings indicate that resilience was understood as continuing

with a 'normal' life and that a couple's relationship and shared sense of resilience was

essential to continue with a 'normal' life. The findings from the review are discussed in

relation to the wider context of literature, with implications for future research discussed.

The importance of dyadic research within dementia is emphasised and the significance of

the relationship in living well.

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Part One: Systematic Literature Review

## Resilience in dementia from a dyadic perspective: A systematic literature review

Lucy Conway\*, Dr Chris Clarke, Dr Emma Wolverson
School of Health and Social Work,
University of Hull, Cottingham Road, Hull, HU6 7RX

\*Corresponding Author: Tel: +44 1482 464106,

 $Email\ address:\ L.K. Conway @\ 2012. hull. ac.uk$ 

This paper is written in the format ready for submission to  $Aging \ \& \ Mental \ Health$ 

Please see Appendix A for the instructions for contributors

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**Abstract** 

**Objectives** 

Resilience may be one psycho-social resource that supports living well in dementia.

This review aimed to synthesise research into resilience in relation to people living with

dementia (PLwD), caregivers and dementia dyads in order to understand the factors

which maintain resilience and the extent to which a dyadic perspective has been adopted

in the literature to date.

Method

Ten papers were included within the review. Data was extracted using a standardised

data extraction form, similarities and differences between papers explored and

synthesised using narrative synthesis. The methodological quality of the studies was

also evaluated.

Results

The findings were categorised into 3 themes from which further subthemes were

developed. The themes included: individual resources (including acceptance, positivity

and identity), community resources (including support and activities) and societal

resources.

**Conclusion** 

Findings from this review suggest that caregivers and PLwD utilise individual,

community and societal resources to maintain their resilience. Whilst dyadic research

was limited, findings suggest the importance of the couple's relationship in the

maintenance of resilience but further dyadic research is needed to support this.

Key words: resilience, dementia, couples, dyads, review

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#### Introduction

Resilience can be understood as a person's ability to successfully adapt and flourish despite facing adversities (Luthar, Cicchetti & Becker, 2000); and relates to positive outcomes such as the maintenance of well-being (Wilmshurst, Peele & Wilmshurst, 2011). However, research has highlighted ambiguity surrounding how best to define and measure resilience (Ungar, 2011).

Informal caregiving is associated with adversity, with research suggesting that caregiving can result in potential threats to quality of life (Zauszniewski, Bekhet & Suresky, 2010). The extent to which caregivers can maintain resilience is, therefore, a key issue. Resilience enables family caregivers to overcome the adversity associated with their role whilst maintaining their own health and well-being (Saunders, 2003; Walton-Moss, Gerson & Rose, 2005). Windle and Bennett (2011) developed a resilience framework (Figure 1) to provide an explanation of the factors which develop resilience in caregivers of older adults despite the adversities and challenges of caregiving.

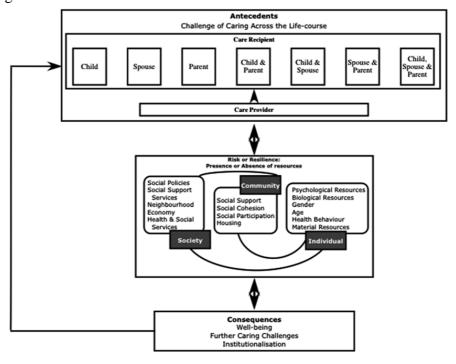


Figure 1. The resilience framework in caring relationships (Windle & Bennett, 2011)

This framework suggests that there are key areas of a caregiver's life which can potentially offer resources to foster resilience, at an individual, community and society level, emphasising the importance of drawing from many resource domains to increase well-being and successfully face the challenges of caregiving.

Research suggests that dementia caregivers are at risk of increased stress, depression and burden (Cassie & Sanders, 2008) in comparison to other caregivers due to: the increased time, impact on employment, increased caregiver strain and disagreements within the family (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999). Despite this increased stress some dementia caregivers do not experience such difficulties (Gaugler, Davey, Pearlin & Zarit, 2000), suggesting that caregivers of people living with dementia (PLwD) can also be resilient.

Research into dementia caregivers suggests that resilience can improve both physical and mental well-being (Fernández-Lansac, Crespo, Cáceres, & Rodríguez-Poyo, 2012) and reduce the institutionalisation and death of PLwD (Gaugler, Kane & Newcomer, 2006). Correlations have also been found between resilience and social support (Fernández-Lansac et al., 2012), coping strategies (Sun, 2014; Truzzi et al., 2014; Wilks, Little, Gough & Spurlock, 2011), positive outlook (Bekhet, 2013) and maintaining optimism (Contador, Fernández-Calvo, Palenzuela, Miguéis & Ramos, 2012), as well as decreased burden (Bekhet, 2013; Fernández-Lansac et al., 2012; Gaugler, Kane & Newcomer, 2007).

Previous reviews looking at research involving caregivers of PLwD have shed light on the factors that may enable this group of caregivers to maintain resilience, offering some support for the application of Windle and Bennett's (2011) framework. Dias et al. (2015) reported biological, psychosocial and social support factors whilst Manzini Brigola, Pavarini and Vale (2016) synthesised factors affecting resilience into the caregiver, the care recipient and the context of the care. Manzini, et al. (2016) found

the relationship between caregivers and PLwD to be important, however this finding seemed somewhat overlooked within the review.

In contrast to the existing literature on dementia caregiving, relatively less is known about how PLwD maintain resilience, possibly reflecting an assumption that PLwD cannot live well and/or age successfully (Harris, 2008). Despite such assumptions Harris (2016) emphasises the importance of resilience research in understanding and promoting living well with dementia. Similarly, there is little known about the experience of resilience within and between dyads living with dementia. Braun et al. (2009) highlight the importance of such research to develop a better understanding of the impact the condition has on both members of the dyad and their relationship.

Resilience also impacts couplehood (Wadham, Simpson, Rust & Murray, 2016), described as a sense of togetherness and mutuality within the dyad, providing an explanation for how couples can live together through the challenges of dementia (Hellström, Nolan & Lundh, 2005). From the dyadic perspective of couplehood, caregiving is re-framed as a reciprocal relationship.

This review aimed to synthesise research to understand the factors which facilitate and maintain resilience in the context of living with dementia; with a particular focus on the lived experiences of caregivers and PLwD, and the extent to which a dyadic perspective within dementia research into resilience is considered. This review aimed to answer the following questions:

- (1) How do PLwD and their caregivers experience resilience?
- (2) To what extent has existing research taken a dyadic perspective on resilience in dementia?

#### Method

### Search Strategy

The methodology for this review was developed in accordance with PRISMA guidelines (Moher, Liberati, Tetzlaff & Altman, 2010). The EBSCO search engine was used to search through 5 databases (Academic Search Premier, CINAHL Complete, MEDLINE, PsycARTICLES, and PsycINFO) from inception to April 2018, using terms describing PLwD (Dement\* OR Alzheimer\* OR "Lewy Body" OR Creutzfeldt-jakob OR Wernicke-Korsakoff), aspects of resilience (Resilien\* OR Bounc\* OR hardiness OR hardy OR rebound\*) and caregiving and the relationship (Spouse\* OR Partner\* OR Couple\* OR Dyad\* OR Marriage OR caregiver\* OR "Spousal/familial care\*" OR Supporter\*). Limiters for English language only and peer-reviewed journals only were applied; however, date limiters were not. Search terms were based on previous dyadic literature reviews in dementia (for example Braun et al., 2009) and exploring relevant synonyms for dementia and resilience. A hand search of papers in key journals was also carried out, as well as consulting experts in the field and reviewing references from included literature. To ensure that the review was reflexive in its nature other researchers read a selection of papers included in the review to ensure the validity of analysis. In addition to this, the lead author discussed the papers, the findings of the review and conclusions with the research team, returning to the included papers on a number of occasions to ensure that the findings of these papers were accurately represented in the literature review.

#### Inclusion and Exclusion Criteria

The inclusion and exclusion criteria and a rationale is provided in Tables 1 and 2.

Inclusion Criterion	Rationale
The study aimed to explore the experiences and views of living with dementia and resilience	To find papers which explored the experiences of resilience whilst living with dementia
The study was from the perspective of caregivers or PLwD or both	To develop an understanding of the dyadic perspective of resilience, in accordance with Braun et al. (2009)
The study had a qualitative component	To find papers which considered the lived experiences of PLwD and their caregivers
The study was peer reviewed	To find papers which had been considered to be of good enough quality to be published
The study was written in English	To find papers which were written in the researcher's language due to budget for translation not being available
The study must only include participants over the age of 18	To find papers exploring the experiences of resilience whilst living with dementia for adults

Table 1. The inclusion criteria and rationale

Exclusion Criterion	Rationale
The study aimed to compare or contrast other illnesses to dementia	To ensure that studies were solely focused on the experience of living with dementia
The study involved paid caregivers or professionals	To ensure that only the experience of PLwD and their caregivers were considered rather than that of professionals
The study did not have the experience of living with dementia and resilience as its primary focus (eg: suicidal ideation)	To ensure that studies included in the review were focused on factors maintaining resilience and the lived experience of dementia
The study measured the effectiveness of interventions on levels of resilience	To ensure that studies included in the review were focused on factors maintaining resilience and the lived experience of dementia

Table 2. The exclusion criteria and rationale

### Quality Assessment

Papers were assessed for quality using the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) (Appendix B) allowing for a variety of methodologies to be compared (Souto et al., 2015). A limitation of the MMAT is the low inter-rater reliability, especially in relation to the term 'appropriate consideration' (Souto et al., 2015). Therefore, three papers (30%) were evaluated by a peer researcher, differing scores compared, papers re-read and a final decision made by the lead author (LC) as to its overall quality score. Papers were not excluded based on MMAT scores, but scores were used to critically review the methodology.

### Data Analysis and Synthesis

Data was extracted from the studies using a bespoke data extraction form (Appendix C). Data was synthesised using 'narrative synthesis' described by Popay et al. (2006) in stages: preliminary synthesis and organisation of findings from studies; studying relationships between findings and alternative factors explaining differences; rating the strength of the findings and assessing conclusions. Narrative synthesis was chosen due to its flexibility and ability to synthesise both quantitative and qualitative evidence (Snilstveit, Oliver & Vojtkova, 2012). Findings were separated into resilience maintenance factors from individual, community and societal resources, providing a structure from which interventions can be developed (Cacioppo, Reis & Zautra, 2011). Data was also reviewed from a dyadic perspective using the method proposed by Braun et al. (2009), splitting studies into: research from the perspective of either the caregiver or PLwD; research from the perspective or PLwD but with reference to the other member of the dyad and finally research involving both members of the dyad.

#### **Results**

### Identification of studies

From the electronic database search 407 papers were found. Figure 2 outlines the process taken to select the relevant studies, resulting in the inclusion of 10 papers for the review.

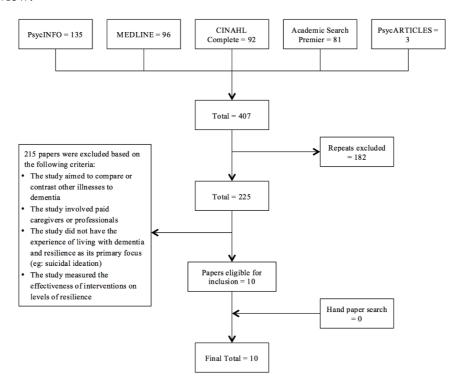


Figure 2. A PRISMA flow diagram detailing the identification of studies

### Characteristics and Quality of Papers

Table 3 presents the characteristics of the papers included within the review. Studies took place in five countries, published over a period of 10 years in nine journals. Sample sizes ranged from one dyad to 80 caregivers (overall sample size n=268). Ages of those involved ranged from 20-90, with the majority of studies stating most participants were women. Seven studies were qualitative, analysed using a variety of methods such as thematic content analysis (n=3), thematic analysis (n=3), grounded theory (n=2), narrative analysis (n=1) and unknown analysis (n=1). The other three studies utilised a mixed methods approach.

Author and Year	Definition of resilience	Aims	Methods	Participants	Setting	Dyadic perspecti ve *	Quality checklist score
Bekhet and Avery (2018)	Growing and flourishing through an adverse situation	Risk and protective factors described within the resilience theory	Qualitative: Open ended questions analysed using content analysis	80 caregivers	Dementia charity (USA)	2	83%
Bull (2014)	Coping and adjusting to adversity	Strategies used to sustain the caregiving role, describing resilience and distress	Mixed Methods: descriptive statistics, interviews transcribed with narrative approach	18 caregivers	Adult Day Care Centres (USA)	2	85%
Deist and Greeff (2015)	The competence and behavioural patterns which individuals and the family maintain despite stressful circumstances	Understand what aids resilience in spouses of PLwD	Mixed Methods: using a Pearson's product-moment correlation for multiple measures** and thematic content analysis for interviews	44 spouses = quantitative measures, 19 of these = interviewed	Memory and genetics clinics (South Africa)	2	75%
Deist and Greeff (2017)	Rebounding and surviving through a crisis or adversity	Understand what aids resilience in children of parents with dementia	Mixed Methods: Pearson's product-moment correlation for multiple measures** and thematic content analysis for interviews	47 adult children caregivers (quantitative), 21 interviewed	Dementia charities (South Africa)	2	75%
Donnellan, Bennett and Soulsby (2015)	Adapting to significant stress and trauma	Can family caregivers be resilient and what do they use to be resilient?	Qualitative: semi-structured interviews analysed using grounded theory and compared to Windle and Bennett's (2011) framework	20 spousal caregivers	Support groups and care homes (UK)	2	100%
Donnellan, Bennett and Soulsby (2017)	Adapting to significant stress and trauma	What are the availability, role and useful aspects of social support in resilience for caregivers for PLwD?	Qualitative: grounded theory approach used to analyse semi-structured interviews	23 spousal caregivers	Support groups and care homes (UK)	2	83%

Harris (2008)	Positively adapting in the face of risk or adversity	How does the resilience of PLwD fit into the health promotion and successful aging paradigms	Qualitative: semi-structured interviews using a person centred approach	2 PLwD and their caregivers	Recruited from larger study of early stage dementia (USA)	3	83%
O'Dwyer, Moyle, Taylor, Creese, and Zimmer- Gembeck, (2017)	Various definitions – aim was to develop their own definition	How family carers understand resilience and what enables them to be resilient	Qualitative: Thematic analysis used to analyse semi-structured interviews	21 caregivers from a larger study were selected	Adverts, events, care providers, social media, word of mouth (Australia)	1	67%
Williamson and Paslawski (2016)	Continuing with a similar life	Develop an understanding of resilience and what helps people to be resilient	Qualitative: Interpretive description of measures and thematic analysis for the semi-structured interviews	12 participants, (7 with dementia, 5 caregivers)	Dementia charity (Canada)	2	83%
Wong, Keller, Schindel Martin and Sutherland (2015)	Adapting to life with dementia whilst maintaining personal identity	Understand the story of resilience in the context of meal times	Qualitative: Thematic analysis for semi-structured longitudinal interviews	1 resilient dyad from larger study	Larger dementia study (Canada)	3	83%

Table 3. Summary of characteristics of studies included in the literature review and the dyadic perspective taken

# \* Dyadic perspective:

- 1. from the perspective of either the caregiver or PLwD
- 2. From the perspective of either the caregiver or PLwD with reference to the other person in the dyad
- 3. Dyadic research involving both people in the dyad

<sup>\*\*</sup>Measures include The Family Attachment Changeability Index-8 (FACI8), The Family Crisis Oriented Personal Evaluation Scale (F-COPES), The Family Hardiness Index (FHI), The Family Problem Solving and Communication (FPSC), The Family Time and Routine Index (FTRI), The Relative and Friend Support Index (RFS) and The Social Support Index (SSI) (Deist & Greeff, 2015, 2017)

### Methodological Quality Assessment

The methodological quality rating for each paper can be found within table 3 (See Appendix D for quality rating summary). In general the overall quality of studies was good, with scores ranging from 67%-100%. All methods and approaches used were appropriate, with research questions, aims and objectives clearly presented. Studies were judged to be lacking in researcher reflexivity, with only three papers considering the influence of the researcher (Bekhet & Avery, 2018; Donnellan Bennett & Souslby., 2015; Harris, 2008), including how questioning impacted on findings (Bekhet & Avery, 2018; Donnellan et al., 2015) and the definition and measurement of resilience (Harris, 2008). Seven of the papers considered how their findings related to the context of the research, in particular how recruitment affected findings (Deist & Greeff, 2015, 2017; Donnellan et al., 2015; Donnellan, Bennett & Soulsby, 2017; O'Dwyer et al., 2017; Williamson & Paslawski, 2016; Wong, Keller & Sutherland, 2015). Poor researcher reflexivity is a common limitation of qualitative research (Newton, Rothlingova, Gutteridge, LeMarchand & Raphael, 2012) affecting the plausibility and trustworthiness of a study (Horsburgh, 2003).

#### Synthesis of Findings

Table 4 presents the themes and subthemes derived from narrative synthesis, with the studies relevant to each subtheme also presented. Due to the complexity of resilience, many of the themes between and within the studies were overlapping, resulting in many possible ways in which findings could be presented and understood.

Themes	Subthemes	Representative studies		
	Acceptance and adaptation	Deist and Greeff (2015, 2017), Donnellan et al. (2015), Harris (2008), O'Dwyer et al. (2017), Williamson and Paslawski (2016), Wong et al. (2015)		
	Identity, self-esteem and self-concept	Bull (2014), Harris (2008), O'Dwyer et al. (2017), Williamson and Paslawski (2016), Wong et al. (2015)		
Individual	Self-care	Bull (2014), Deist and Greeff (2015), et al. (2015), O'Dwyer et al. (2017)		
Resources	Love	Deist and Greeff (2015, 2017), Harris (2008), Wong et al. (2014)		
	Positivity and humour	Bekhet and Avery (2018), Deist and Greeff (2015, 2017), Donnellan et al. (2015), Williamson and Paslawski (2016), Wong et al. (2014)		
	Spirituality	Bull (2014), Deist and Greeff (2015, 2017), Harris (2008)		
	Finances	Deist and Greeff (2015, 2017), Donnellan et al. (2015), O'Dwyer et al. (2017)		
Community Resources	Support	Bekhet and Avery (2018), Deist and Greeff (2015, 2017), Donnellan et al. (2015, 2017), Harris (2008), Williamson and Paslawski (2016)		
	Activities	Harris (2008), Williamson and Paslawski (2016)		
	Information	Bull (2014), Deist and Greeff (2015, 2017) Donnellan et al. (2015, 2017), Williamson and Paslawski (2016)		
Societal Resources		Deist and Greeff (2015, 2017), Donnellan et al. (2015), Harris (2008), O'Dwyer et al. (2017)		

Table 4. Summary of themes and subthemes of the synthesis, within the studies

### Theme 1: Individual Resources

Individual resources were a consistent area of help for caregivers and PLwD; Wong et al. (2015) found that these resources were shared between the couple. However, little consideration was given within the research about the impact that individual resources had on the other member of the dyad. Furthermore, research citing individual resources as vital took place in individualistic cultures, providing a possible explanation for the

focus on such resources. Unfortunately, due to the studies often lacking researcher reflexivity, studies failed to consider the impact that culture had on the findings.

### Acceptance and Adapting

Accepting life with dementia was particularly important for both the caregiver and PLwD in remaining resilient (Deist & Greeff, 2017; Harris, 2008; O'Dwyer et al., 2017, Williamson & Paslawski, 2016), as well as the dyad (Harris, 2008; Wong et al., 2015). Acceptance was conceptualised as coming to terms with the diagnosis, accepting life with dementia and making adjustments (Harris, 2008; Williamson & Paslawski, 2016); and achieved by reminiscing, using humour, maintaining optimistic and having social support. Caregivers also accepted the diagnosis (Williamson & Paslawski, 2016) by utilising open communication, sharing difficulties with others (Deist & Greeff, 2015) and being open about the diagnosis and prognosis (Deist & Greeff, 2017). However, consideration was not given to how PLwD used open communication or how it impacted on them. Caregivers also made downward comparisons (Donnellan et al., 2015), delegating to others, preparing, reciprocating (Donnellan et al., 2015), making changes to their home (Williamson & Paslawski, 2016) and reminiscing with PLwD (Wong et al., 2015). Managing the symptoms of dementia was particularly important for caregivers, achieved via medication, information and strategies (Deist & Greeff, 2015, 2017). Both studies suggesting the importance of managing the symptoms of dementia (Deist and Greeff, 2015; 2017); however both recruited participants from South Africa so this finding may not be generalizable to caregivers from other countries as this was not highlighted as important within other research.

## Identity, self-esteem and self-concept

Some caregivers felt that their resilience had developed from previous experiences and challenges faced (O'Dwyer et al., 2017). Previous experience of caregiving were particularly helpful for facilitating resilience according to both Bull

(2014) and Wong et al. (2015). For PLwD, maintaining a strong self-concept was important (Harris, 2008), ensuring that they were able to maintain a sense of self despite being diagnosed with dementia. Furthermore, ensuring the maintenance of self-esteem was particularly important for both caregivers and people with dementia (Williamson & Paslawski, 2016).

### Self-care

For caregivers, practising self-care was important for the maintenance of resilience: by continuing hobbies (O'Dwyer et al., 2017), physical activity, listening to music, having shared experiences with PLwD and reminiscing (Bull, 2014). This improved the care provided (Bull, 2014), and gave caregivers a break from their responsibilities (Deist & Greeff, 2015). Caregivers also practised self-care by maintaining aspects of their lives prior to the diagnosis, maintaining a sense of normality (Donnellan et al., 2015). Whilst self-care was important for caregivers, the effect this had on PLwD and the dyad was not considered within research.

### Love

The love and commitment that caregivers felt towards family members (Deist & Greeff, 2017) enabled them to make the most of their situation (Deist & Greeff, 2015). Deist and Greeff (2015), Harris (2008) and Wong et al. (2015) found that maintaining a good relationship with the other person in the dyad was important to increase resilience and decrease burden, both for caregivers (Deist & Greeff, 2015) and PLwD (Harris, 2008; Wong et al., 2015). Studies finding the importance of maintaining a good relationship were of good methodological quality, considering researcher reflexivity (Harris, 2008) as well as how findings relate to the context of the study (Deist & Greeff, 2015, 2017; Wong et al., 2015).

### Positivity and humour

Resilience was also maintained by caregiver positivity, hope and optimism (Deist & Greeff, 2015, 2017; Donnellan et al., 2015; Harris, 2008; Wong et al., 2015). This was achieved by humour, practising self-care, taking things one day at a time (Deist & Greeff, 2015) and avoiding thoughts about the future (Deist & Greeff, 2017), enabling caregivers to focus on the present rather than becoming preoccupied with thoughts about what the future may hold for them. Humour was particularly important for caregivers and PLwD (Deist & Greeff, 2015; Donnellan et al., 2015; Wong et al., 2015; Williamson & Paslawski, 2016), facilitating positivity (Deist & Greeff, 2015) and easing difficult situations (Wong et al., 2015). Studies also highlighted how positivity and humour are important for caregivers (Deist & Greeff, 2015, 2017; Donnellan et al., 2015) and dyads (Wong et al., 2015), whilst positivity was more difficult for some to achieve (Bekhet & Avery, 2018). Difficulties in maintaining positivity could be attributed to participants not considering themselves resilient (Bekhet & Avery, 2018), whilst other studies purposively sampled people who were resilient (for example Wong et al., 2015). Alternatively, differences in findings may be due to disparities between questioning style, with Bekhet and Avery (2018) asking two open ended questions about what it is like to care for PLwD, whilst other studies asked specific resilience focused questions such as what helped participants to cope with and adapt to the dementia (Deist & Greeff, 2015, 2017, Williamson & Paslawski, 2016).

### **Spirituality**

Spirituality was used to sustain a sense of self and remain resilient in caregivers (Bull, 2014) and PLwD (Harris, 2008), increasing strength, providing meaning to the experience (Bull, 2014), facilitating a positive attitude (Deist & Greeff, 2015, 2017), with the strength that God provided helping caregivers adapt and deal with their problems (Deist & Greeff, 2015, 2017). However, not all research suggests the

importance of spirituality, both qualitatively (Williamson & Paslawski, 2016) and quantitatively (Deist & Greeff, 2015, 2017). Williamson and Paslawski (2016) suggested that small sample sizes could provide an explanation for why they did not find spirituality to be an important contributor to resilience within their participants. Alternatively cultural differences may impact on how caregivers and PLwD utilise spirituality to cope and adapt to life with dementia.

### **Finances**

The research suggested that finances were an important factor contributing to resilience in caregivers, with some consideration given to how this could benefit PLwD. Financial stability was important in enabling families to adapt to life with dementia (Deist & Greeff, 2015, 2017), providing a better quality of life for caregivers and PLwD (Donnellan et al., 2015) and access groups to increase emotional support (O'Dwyer et al., 2017). However, the importance of finances was not mentioned within all caregiver research, a possible explanation for this may be that countries such as the UK offer free healthcare and means tested social services support. Whilst waiting lists within the UK can affect access to services, all caregivers should have the opportunity to access support for free or at a reduced cost when needed.

### Theme 2: Community Resources

A consistent finding across studies was that community resources were important in developing and maintaining resilience both in caregivers and PLwD; however, research to date is limited in its investigation of this aspect with respect to couple's experiences.

### Support

Support from others was important for both caregivers and PLwD in maintaining resilience (Bekhet & Avery 2018; Deist & Greeff, 2015, 2017; Donnellan et al., 2015, 2017; Harris, 2008; Williamson & Paslawski, 2016). However, within

research little consideration was given to how recruitment of participants from dementia charities and support groups affected findings, as the support of family, friends and the wider community are emphasised within these groups, suggesting possible inadvertent selection bias.

The support of family provided PLwD and caregivers (Harris, 2008; Williamson & Paslawski, 2016) with emotional and physical support (Deist & Greeff, 2015, 2017). However, in caregivers this was preferred at a distance to maintain independence (Donnellan et al., 2015, 2017). Contradictory to this, participants within Bekhet and Avery's (2018) study felt they would have benefitted from more familial support. Differences with these findings may be due to participants within this study not identifying as resilient compared to research which purposively sampled resilient people, or alternatively could be due to cultural differences between the value placed on familial support within the USA and the UK.

Friendships were important for caregivers (Donnellan et al., 2017), which quantitatively predicted family adaptation in spousal caregivers (Deist & Greeff, 2015). Interestingly, support of friends was not vital for other familial caregivers (Deist & Greeff, 2017), possibly due to limited time to access this support as a result of having other commitments such as children and work.

Other places that offered support included retirement homes (Deist & Greeff, 2015), dementia support groups (Deist & Greeff, 2017; Donnellan et al., 2015, Harris, 2008), and churches (Donnellan et al., 2017) offering practical support, crisis management (Donnellan et al., 2017) and social interaction (Williamson & Paslawski, 2016). This enabled caregivers to learn and share information about dementia, (Donnellan et al., 2015). Community support quantitatively predicted family adaptation in spousal and familial caregivers (Deist & Greeff, 2015; 2017); however, some caregivers felt this support could be improved (Deist & Greeff, 2015).

#### Activities

Continued involvement in activities which PLwD participated in before their diagnosis was important for PLwD (Harris, 2008), as well as providing respite for caregivers, social interaction and emotional regulation for both caregivers and PLwD (Williamson & Paslawski, 2016). Interestingly, research has not considered whether it was equally important for caregivers to continue participating in the same activities they had done prior to the diagnosis. It could be argued that this reduces a loved one supporting a PLwD to just a caregiver.

### Information

Using community and social resources to gather information and gain knowledge was important for caregivers to help manage dementia (Deist & Greeff, 2015, 2017), enabling learning about dementia. This prepared caregivers for the future (Bull, 2014; Williamson & Paslawski, 2016) and decreased fears about the future (Williamson & Paslawski, 2016). For some knowing about the future was not helpful in maintaining resilience (Deist & Greeff, 2017); however, it is not clear why knowledge about the future is helpful for some (Bull, 2014; Williamson & Paslawski, 2016) and not for others (Deist & Greeff, 2017). Sharing and receiving information also provided social support for caregivers (Donnellan et al., 2015, 2017), as well as the opportunity to educate the general public and increase awareness (Williamson & Paslawski, 2016).

#### Theme 3: Societal Resources

Society-level resources were investigated with respect to caregiver resilience; included studies often failed to explicitly investigate how resources at this level may facilitate resilience for dyads or for individuals with dementia.

For caregivers, access to respite services was key in maintaining resilience (Deist & Greeff, 2015, 2017; Donnellan et al., 2015; O'Dwyer et al., 2017), as well as

day care, home help and support groups (Donnellan et al., 2015; Williamson & Paslawski, 2016). Caregivers and PLwD also valued support from healthcare professionals (Deist & Greeff, 2015, 2017; Harris, 2008) providing respite for caregivers (Deist & Greeff, 2015, 2017).

Societal resources were rarely considered within resilience research, with those finding society resources useful recruited from support groups (Donnellan et al., 2015; Williamson & Paslawksi, 2016), dementia charities (Deist & Greeff, 2017) and health centres (Deist & Greeff, 2017), from which societal resources may be more accessible. Williamson and Paslawksi (2016) suggests that participants' ability to access support groups illustrated resilience, however, consideration was not given to how recruitment from support groups impacted on the findings and conclusions drawn.

### **Discussion**

This literature review aimed to develop a clearer understanding of factors that enable PLwD and their caregivers to maintain resilience from a dyadic perspective. Findings propose that resilience is maintained through a number of factors that can be categorised into individual, community and societal resources consistent within other resilience research (Windle & Bennett, 2011; Ungar, 2011). However, it is important to consider the complex nature of resilience, as findings from this review state that factors which may increase resilience in some, may have no benefit or impede resilience in others (Donnellan et al., 2015). For example, having knowledge about the future decreased fears and increased resilience in some (Williamson & Paslawski, 2016) whilst being unhelpful for others (Deist & Greeff, 2017).

Another key finding is the paucity of studies investigating factors associated with resilience amongst PLwD and dyads, possibly due to the assumption that PLwD cannot live well (Harris, 2008). This review presents many factors that affect caregiver

resilience; however it highlights that the impact this has on PLwD or their dyad is rarely considered within research. Dyadic research by Wong et al. (2015) highlights the importance of the relationship within the dyad and the impact this has on resilience. However, as this is a case study generalising findings is problematic and further research is required. Whilst few studies considered the views of PLwD there was evidence that PLwD can be resilient and live well with dementia (Harris, 2008; Williamson & Paslawski, 2016; Wong et al., 2015), therefore more research is needed to explore and understand resilience in this marginalised group of individuals. In addition to this, there also needs to be further resilience research which is theory driven, enabling an agreed definition and integrated understanding of resilience to be developed (Dias et al., 2015).

Dias et al. (2015) conducted a literature review focusing on factors associated with resilience in dementia caregivers and found individual resources and social support to be important aspects of resilience, in line with this review. Manzini et al. (2016) also stress the importance of social and family support and the relationship between caregivers and PLwD as was found in the current review. Findings from these reviews and the current review therefore suggest the importance of both individual and community resources in maintaining resilience in caregivers whilst supporting PLwD. The current reviews adds to the previous reviews (Dias et al., 2015; Manzini et al., 2016) by including research from the perspective of PLwD and dyads, whilst previous reviews have focused just on caregivers (Dias et al., 2015; Manzini et al., 2016). The current review indicates that PLwD and dyads also benefit from similar resources to maintain and develop resilience, a key finding due to the assumption that PLwD cannot live well with dementia or age successfully (Harris, 2008). Due to the limited research involving PLwD and the dyad more research is needed in this area.

Whilst limited, the current review also highlights the importance of societal resources on the maintenance of resilience within caregivers, which neither Dias et al. (2015) nor Manzini et al. (2016) found. In contrast to the current review, Manzini et al. (2016) found that the ethnicity of caregivers was important for the development of resilience. Differences in findings may be due to a lack of ethnic diversity within the research included in the current review, possibly due to the limiters of English language applied, or due to variations in the inclusion and exclusion criteria, as Manzini et al. (2016) included any studies which were associated with resilience, whilst the current review only included research which aimed to explore the experiences and views of living with dementia and resilience. The current review therefore adds to previous reviews as it is able to be more specific and focused in its exploration of resilience in dementia due to the inclusion criteria that research must aim to study resilience.

This review highlights that for caregivers of PLwD, similar resources are utilised to those included in the resilience framework for caregivers of older adults (Windle & Bennett, 2011), despite research proposing that the caregiving experience of caregiving for PLwD is more stressful (Cassie & Sanders, 2008; Ory et al., 1999). Furthermore, the current review included research with PLwD, whilst other reviews have focused on research into caregiver resilience (Dias et al., 2015; Manzini et al., 2016). Factors affecting resilience in research including PLwD also match certain aspects of Windle and Bennett's (2011) framework, indicating that these factors do not only facilitate resilience in caregivers, but also in care recipients; contradictory to the assumption that PLwD cannot be resilient and 'live well with dementia' (Harris, 2008).

Similarities in findings between this review and Windle and Bennett's (2011) framework may have been due to a number of papers within the review choosing to follow the Windle and Bennett (2011) framework as a structure for their results as well as the current review utilising the framework whilst synthesising the papers. The

framework provided a lens from which the papers included in this review could be viewed, enabling a structured approach to be taken, however, a limitation may be that other findings which did not appear to fit into the framework may have been overlooked.

When considering ways in which the findings from this review differed to Windle and Bennett's (2011) resilience framework, the review highlights that for both caregivers and PLwD engaging in self-care, maintaining a former identity, sustaining faith and spirituality all constitute dementia-specific factors that can maintain resilience. Variances from the framework may be due to differences in experiences between living with dementia and ageing generally, but low sample sizes in included studies prompt caution with regard to this interpretation. Windle and Bennett (2011) also highlight the importance of policies and legislation, creating an environment in which the person can adapt to life as a caregiver and ultimately develop resilience. Interestingly, within the current review neither caregivers or PLwD mentioned policies and legislation to be an important aspect of resilience. This may be due to the complexities of policies and legislation resulting in the general public having limited knowledge of these. It would be expected that professionals working with PLwD would have knowledge of policies and legislation and therefore may have opinions on how they feel this impacts on resilience, however, the current review chose the exclude research involving professionals. Further research into the impact that policies and legislation have on caregivers and PLwD may provide further insight to this area of Windle and Bennett's (2011) framework.

Research from this review also provided further information on couples' relationships and their impact on resilience (Wong et al., 2015). Research which considers the caregiving relationship enables an understanding of couplehood to be developed (Hellström, Nolan, & Lundh (2005), giving further insight into shared

experiences of living with dementia and the needs of both the care recipient and caregivers (Ryan, Nolan, Reid & Enderby, 2008). Furthermore, dyadic research enables us to understand how a person is able to give or receive care within the relationship and its' associations with attachment theory (Browne & Shlosberg, 2006). The experience of receiving a diagnosis of dementia is likely to elicit worries about having a lack of control (Miesen, 1993), often leading to an increase in attachment behaviours (Miesen, 2010), such as seeking proximity. Secure attachment styles of both the caregiver and PLwD have been found to be important for the giving or receiving of care within the relationship, as securely attached dyads lead to the reduction of caregiver burden (Magai & Cohen, 1998) and the delivery of more sensitive and appropriate care (Van Assche et al., 2013). Within research the links between attachment and resilience in PLwD and caregivers are yet to be studied, however, Atwool (2006) states that familial support which has been outlined within the field of dementia research as being imperative for resilience, cannot occur without some form of attachment. Therefore, it is probable that in order to develop resilience as a dyad an attachment must be maintained. Further research is necessary to understand how resilience and attachment are related within PLwD and their caregivers.

Findings from this review highlight similarities between dyadic resilience and family resilience (Walsh, 2011), in which adversities affect the whole family unit and therefore the whole family unit are involved in the recovery from such an adversity. Other dyadic resilience research has emphasised the importance of relational aspects of resilience, with Lim, Shon, Paek and Daly (2014) recommending that cancer interventions should be couple-based to aid the development of resilience and adjustment to life with cancer. Unfortunately, dyadic research within dementia is currently limited (Braun et al., 2009) and existing research has small sample sizes.

Therefore, further research into dyadic resilience in dementia is necessary to develop a better understanding of this concept in order to consider possible interventions.

#### Limitations

Limitations of this review refer both to the methodological quality of the research and the quality of this review. Limitations of the studies within the current review included the impact that recruiting participants from support groups may have had on findings (Deist & Greeff, 2015, 2017; Donnellan et al., 2015, 2017; Williamson & Paslawski, 2016), difficulty and diversity in measuring resilience (Wong et al., 2015), not controlling for different types of dementia (Williamson & Paslawski, 2016) and concerns that participants only considered themselves to be resilient because they had not yet experienced the adversity of severe dementia (O'Dwyer et al., 2017). Another limitation is that currently there is no agreed upon definition of resilience within dementia. Chosen definitions within the studies varied, offering a potential explanation for some of the differences found between studies. Dias et al. (2015) therefore highlights the need for a theoretical framework for resilience from which a unified definition can be based upon. In addition to these limitations, many of the studies relied on the self-reported experiences of the participants. It is possible that participants may have inaccurately portrayed their experiences of life with dementia due to social desirability or cohort effects.

Methodological limitations of the review include combining findings from quantitative and qualitative research, which made it difficult to synthesise and organise varying findings in a replicable way. In addition to this on several occasions findings could be arranged into a number of themes, as resources and factors were often reported simultaneously within the research, highlighting the complexity by which resilience can be conceptualised (Donnellan et al., 2015).

### Implications for Research and Practice

This review offers an improved understanding of factors that may help develop and maintain resilience amongst caregivers, PLwD and dyads. Such findings are pertinent to interventions aimed at increasing resilience whilst living with dementia, and therefore may inform how resilience interventions are developed and delivered in the future; such as narrative-based reminiscence (Purves, Savundranayagam, Kelson, Astell, & Phinney, 2011) for PLwD, which aims to promote positive social interaction, strengthen relationships and generates shared experiences with others. To build on these findings, further research in the following areas is necessary:

- Develop an understanding of how resilience research from the perspective of
  one member of the dyad affects the other person, enabling a relational
  understanding of resilience to be developed.
- Build on the knowledge from case studies from a dyadic perspective to develop
  a more detailed understanding of the factors of resilience in couples living with
  dementia, considering in particular the impact of the relationship on resilience.
- Develop a specific framework of resilience within dementia either from the perspective of caregivers, PLwD or the dyad.
- Understand the implications that policies and legislation have on individual resources used to develop and maintain resilience in the context of dementia and dementia caregiving.

### Conclusion

To the author's knowledge, this is the first review to synthesise research into resilience in dementia by considering lived experiences from a dyadic perspective. The review clearly highlights the disparity between the amount of research considered from the perspective of the caregiver and that of the PLwD, in addition to emphasising the lack

of dyadic research within dementia resilience research. The review therefore proposes the need for further research into resilience from either the perspective of PLwD or the dyads.

The review found that both caregivers and PLwD utilise a number of resources to help maintain resilience. These findings can be organised into individual, community and societal resources, mapping on to the framework proposed by Windle and Bennett (2011) for resilience in caregivers of older adults. The finding that both caregivers and PLwD utilise the same resources to maintain resilience is key, indicating that resilience interventions should be delivered to both caregivers and PLwD. However, the review does emphasise that resilience is complex, and therefore factors which may increase resilience in some, may have no benefit or impede resilience in others (Donnellan et al., 2015), highlighting the need for an individualised and person-centred approach to resilience interventions.

Finally, due to the complexities of resilience outlined within this review, further resilience research which is theory driven must be completed. Such research will enable the development of an integrated understanding of resilience within the context of dementia and subsequently a definition of resilience to be developed.

### **Disclosure of Interest**

No potential conflict of interest was reported by the authors.

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Part Two: Empirical Paper

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Lucy Conway\*, Dr Chris Clarke, Dr Emma Wolverson
School of Health and Social Work,
University of Hull, Cottingham Road, Hull, HU6 7RX

\*Corresponding Author: Tel: +44 1482 464106,

Email address: L.K.Conway@2012.hull.ac.uk

This paper is written in the format ready for submission to the journal

\*Dementia\*

Please see Appendix E for the instructions for contributors

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**Abstract** 

Resilience is a concept which may help explain how people are able to live well with

dementia (Harris, 2016). Existing resilience research in dementia focuses on the

caregiver and relatively little is known about how the dyad experience resilience. This

study aimed to develop a theory of shared resilience through Constructivist Grounded

Theory by asking 12 dyads living with dementia their understanding of resilience, what

helped to develop and maintain their resilience and how resilience impacts on their

relationship and well-being. Findings indicate that resilience was understood as

continuing with a 'normal' life as a couple rather than flourishing, as research outside of

dementia has suggested. The couple's relationship and shared sense of resilience was

essential in continuing with a 'normal' life and to continue to develop further resilience.

These findings emphasise the importance of dyadic research to develop a clearer

understanding of the experience of living with dementia and the significance of the

relationship in facilitating living well.

**Keywords:** caregiver, couplehood, dementia, dyads, resilience

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## Introduction

Resilience is a concept which may provide an explanation for why some people are able to continue to live meaningful lives despite facing the adversities associated with a dementia diagnosis (Harris, 2016). This ensures that a strength-based approach is used rather than a deficit model of illness (Windle 2011). Such an approach is vital within dementia, empowering people living with dementia (PLwD) and their caregivers by harnessing their strengths and promoting our understanding of what it means to live well with dementia (Harris, 2016).

Lepore and Revenson (2006) outlined three dimensions from which the construct of resilience can be understood: 'resistant resilience', remaining strong in the face of adversity; 'recovery resilience', bouncing back to previous functioning after facing adversity; and finally, 'reconfiguration resilience', going through a period of growth after adversity. This form of resilience is separate to post-traumatic growth although research often fails to distinguish between them (Westphal & Bonanno, 2007).

To date, the majority of research into resilience and dementia has focused on the caregiver, with findings indicating that resilience can increase both physical and mental well-being by reducing anxiety, depression, drug-use and by fostering coping skills (Fernández-Lansac, Crespo, Cáceres & Rodríguez-Poyo, 2012). High levels of caregiver resilience have also been found to be beneficial for PLwD, by reducing rates of care recipient institutionalisation and even death (Gaugler, Kane & Newcomer, 2007). Unfortunately, there has been limited resilience research conducted with PLwD, possibly due to an assumption that PLwD cannot live well and/or age successfully (Harris, 2008) and / or that they may not be able to sustain or develop resilience. Lepore, Shuman, Wiener and Gould (2017) also suggested that the lack of representation of PLwD within research might be due to complications with gaining

ethical approval, informed consent from participants and caregivers denying PLwD the opportunity to take part in research. It could be argued that this lack of research implicitly marginalises the experiences of PLwD and de-contextualises the caregiving relationship.

An important way to comprehend the experience of resilience and living with dementia is to take a dyadic perspective to research. This enables the appreciation of the relational capacity of both PLwD and caregivers (Braun et al., 2009) through the exploration of couples' shared understanding of the experience of living with dementia (Daniels, Lamson & Hodgson, 2007; Molyneaux, Butchard, Simpson & Murray, 2012), the relational capacity (Kitwood, 1997) and the needs of both the care recipient and the caregiver (Ryan, Nolan, Reid & Enderby, 2008). Unfortunately, research into couples living with dementia is rare, with existing research focusing on the caregiver in isolation. This has attracted criticism that there has been an overreliance on caregivers within research and an associated neglect of the perspective of the person with dementia (Clarke, Keady & Wilkinson, 2002).

Wadham, Simpson, Rust and Murray (2016) highlight the potential importance of a shared sense of resilience for couples living with dementia, suggesting that a shared sense of resilience may enable couples to maintain couplehood. Couplehood, a mutual sense of togetherness and reciprocity in the dyad, provides insight into how couples live together with the challenges that dementia brings (Hellström, Nolan & Lundh, 2005). Hellström, Nolan and Lundh (2007) found that couplehood involved trying to maintain a quality of life with their spouse for as long as possible, achieved by talking things through, being appreciative of each other, showing affection, attempting to make the best of things and keep the peace. Wadham et al. (2016) highlights the importance of

maintaining couplehood for couples living with dementia, and suggests that resilience of couples may enable them to achieve and maintain a sense of couplehood.

A significant barrier to furthering our understanding of resilience with respect to living with dementia is that there remain few theoretical frameworks from which research can be based. At present, within dementia, definitions of resilience vary widely and include: adjusting to adversity, a personal attribute, well-being and inner strength, level of burden and sufficient social support (Dias et al., 2015). Definitions of resilience proposed vary between professionals and caregivers, with caregivers focusing more on social support and the relationship with PLwD, whilst professionals prioritise maintaining quality of life and coping (Joling et al., 2017). Differences between how resilience is conceptualised by professionals and caregivers highlight the importance of developing a person-centred definition of resilience which is meaningful for caregivers and PLwD. Dias et al. (2015) suggest that varying definitions of resilience within research reflects a lack of an overarching theoretical framework from which definitions can be based, suggesting the development of such a framework is important for future research.

Outside of dementia care, research into resilience suggests that to maintain resilience a person must use their individual resources, as well as resources from their environment (Ungar, 2011). Whilst prominent frameworks of resilience exist (for example Windle & Bennett, 2011) and have been cited in relation to caregivers within dementia literature (for example Donnellan, Bennett & Soulsby, 2015), they are not specific to dementia. This is problematic because it assumes that the experience of resilience is the same both for caregivers of older adults and caregivers of PLwD. Donnellan et al. (2015) suggest that the framework lacks a contextualised approach for understanding resilience in caregivers of PLwD, after finding that what facilitates resilience in some caregivers may

hinder resilience in others. Furthermore, O'Dwyer, Moyle, Taylor, Creese and Zimmer-Gembeck (2017) highlight that in dementia caregivers there is a continual growth of resilience over time and therefore suggests that the framework by Windle and Bennett (2011) could be improved by conceptualising it as a cyclical process, to describe the way in which resilience continually develops.

In summary, whilst resilience can have clear benefits for dementia caregivers (Fernández-Lansac, et al., 2012) there is currently a limited understanding of how resilience is experienced and maintained within a dyadic context. Given the need for a clearer definition and theoretical framework of resilience in dementia, particularly in relation to the perspective of PLwD and the dyad, this study aimed to generate a theory of resilience using a constructivist grounded theory approach. This study therefore aimed to explore what resilience means in the context of couplehood in dementia, how dyads experience a shared sense of resilience, how they develop and maintain resilience and how this impacts upon their relationship and shared well-being.

#### Method

#### **Design**

A qualitative Constructivist Grounded Theory approach (Charmaz, 2006) was utilised, enabling differences between people to be researched and considered fully (Charmaz, 2014). Such an approach reflects an assumption that resilience is complex, enabling the research to compare and contrast how dyads understand shared resilience, developing this into a theory. The researcher took a constructionist stance in which there was no objective truth to uncover (Guba & Lincoln, 1994). A constructivist approach to research acknowledges that the researcher may too have their assumptions and preconceptions which may impact upon how they understand the experiences of the

participants (Charmaz, 2006). Within the study there was an assumption that people with dementia can and should be able to demonstrate resilience. There was also an assumption that caregivers and PLwD would be able to produce meaningful explanations of their understanding of resilience and their experience of living with dementia and resilience which could then be explored qualitatively by the researcher. Finally, there was an assumption that the researcher would be able to arrange the qualitative findings into a theory which would provide an explanation of shared resilience in dyads living with dementia.

Within qualitative research, researcher reflexivity is important to ensure that researchers can consider the influence they have had on the research and its' findings (Finlay, 2002). Within Constructivist Grounded Theory this ensures that the emergent theory remains grounded in the data collected (Ramalho, Adams, Huggard & Hoare, 2015). Constructivist Grounded Theory acknowledges ideas of double hermeneutics, that theories are developed through interactions and experiences of the researcher (Charmaz, 2006). Therefore, Charmaz (2017) suggests that developing methodological selfconsciousness is essential to ensure reflexivity, in which the researcher is aware of their world-views, priorities and privileges, and how these may impact on the collection and analysis of data. In order to consider methodological self-consciousness, the lead research kept a reflective journal (See Appendix P for the researcher's reflective statement). The lead researcher also reflected upon their experiences with PLwD considering how these may have shaped the research, such as reflecting on working professionally with PLwD in addition to family experiences of dementia. The lead researcher reflected on how these experiences shaped their assumption that people are able to live well with dementia, living a fulfilling and meaningful life despite their diagnosis. Supervision with the research team was utilised to limit researcher bias and ensure methodological self-consciousness, in which previous experiences, assumptions

and world-views were discussed, in addition to the process of data collection, data analysis and the development of the emergent theory.

#### Sample

Within Constructivist Grounded Theory there are no agreed standard sample sizes; the aim of the data collection being to reach data saturation. This is when further collection of data will not lead to additional information related to the research question (Charmaz, 2006). Guest, Bunce and Johnson (2006) suggest this could be achieved between 6-12 interviews. Dyads were purposively sampled in this study, i.e. dyads who considered themselves to be resilient and were motivated to take part in the study.

Participants were recruited from across Yorkshire (UK) via an NHS Foundation Trust, local memory cafés run by the Alzheimer's Society and the Join Dementia Research database. Table 5 provides an overview of the inclusion and exclusion criteria for the research.

#### **Inclusion Criterion**

#### **Exclusion Criterion**

One member of the dyad had to be living with dementia and aged over 65.

The other member of the dyad had to be over 18, their spouse or partner and identify as their caregiver.

The dyad had to be living together within the community, as moving into residential care can significantly change roles and the relationship (Graneheim, Johansson & Lindgren, 2014).

Both participants had to have capacity to give consent to be involved in the study.

Dyads with a diagnosis of young onset dementia, as research suggests that their experience of dementia may differ from those diagnosed with dementia after the age of 65 (Clemerson, Walsh & Isaac, 2014).

Participants who had received their diagnosis less than 3 months ago, as Vernooij-Dassen, Derksen, Scheltens and Moniz-Cook (2006) suggest it takes 3 months to adjust to the diagnosis and this study was interested in the experience of living with dementia rather than that of being diagnosed.

Table 5. The inclusion and exclusion criteria for participants with the rationale where required

Twelve dyads took part in total. Ten males and two females were diagnosed with dementia, with a range of diagnoses: mixed (n=5), Alzheimer's Dementia (n=4), Vascular Dementia (n=1), Lewy Body Dementia (n=1) and unknown (n=1). Participants received their diagnosis between 3 months - 6 years ago (mean = 2.9 years). The age of PLwD ranged from 67-89 (mean = 75.3). Of the caregivers taking part in the research, 10 were female and 2 were male, ranging in age from 53-87 (mean = 72.3). Eleven of the dyads interviewed were married, ranging from 22-66 years (mean = 46.2 years); 1 dyad was unmarried, but had been in a relationship for 10 years. All participants interviewed were White British. Table 6 describes characteristics and pseudonyms of the participants.

Dyad surname pseudonym	Age of PLwD	Age of partner	Years together	Time since diagnosis
Jones	71	69	49	2 years
Davies	67	53	28	1 year
Roberts	75	74	51	1 year
Brown	89	87	66	6 years
Smith	76	72	52	5 years
Evans	74	84	24	2 years
Williams	81	69	10 *	3 years
Thompson	69	69	50	3 years
Green	75	75	59	3 years
Taylor	74	63	22	3 months
Wood	81	81	60	2 years
Edwards	72	71	47	6 years

Table 6. Participant characteristics. \* not married but in a relationship for 10 years

#### **Ethics and Consent**

The London – Riverside Research Ethics Committee and the Health and Research Authority (approval number: 17/LO/1121) (See Appendix F and G) granted ethical

approval prior to commencing the study. Each dyad was provided with verbal and written information (See Appendix I) about the study prior to gaining consent. An assessment of capacity to give informed consent was made by the lead researcher (LC), assessed by ensuring both members of the dyad were able to understand and retain information about the study, weigh up the information in order to make a decision about participating in the study and then communicate this decision to the researcher. Both members of the dyad were asked to complete written consent forms (See Appendix J). One dyad who expressed interest were excluded due to lacking capacity to give consent.

#### **Data Collection**

All dyads were interviewed in their home once. Each dyad completed a demographic questionnaire (See Appendix K). The interviews then commenced, with the researcher interviewing the dyad together, allowing an opportunity for shared meanings to be developed and new knowledge to be generated between the dyad (Seymour, Dix, & Eardley, 1995). Dyads were asked about their understanding of resilience, what had helped to develop and maintain their resilience as a couple and what impact their resilience had had on their relationship and shared well-being. Consistent with a grounded theory approach, theoretical sampling was used to help clarify and address gaps in any emergent theory (Charmaz, 2006). This centred on adding and adapting interview questions over the course of data collection on the basis of initial coding and constant comparative analysis (See Appendix L). Both members of each dyad participated in the interviews; however, participation was not always even as PLwD led some interviews, whilst in others it was their partner who led. Interviews ranged in length from 37-75 minutes (mean = 56 minutes and 45 seconds). Dyads were invited to provide further information should they choose following the interviews via email or telephone, with one dyad responding. In accordance with Charmaz (2014), saturation

was reached as further data collection did not give further detail to the categories or theory. Consideration of data saturation, time constraints and management of data therefore determined the sample size of 12 dyads.

#### Analysis

The researcher transcribed each interview prior to the next interview, allowing for constant comparative analysis. Analysis of data was carried out referring to recommendations made by Charmaz (2006). Coding of the transcripts began with initial coding, in which data was coded line by line, involving the researcher identifying key quotes and ideas within the margin of the transcriptions (Appendix M). The researcher then categorised the initial codes that were most frequently mentioned and most significant, using focused coding to analyse larger sections of data. Focused codes were then used for theoretical coding in which the categories developed by focused coding were compared, developing overarching themes in which interrelationships between them were conceptualised and mapped, forming an emergent theory of shared resilience (Appendix N). This was an iterative process in which the researcher revisited earlier codes, comparing these repeatedly to emerging overarching themes. The researcher also consulted previous research and literature examining resilience and dementia for similarities and differences and to see how similar findings had been categorised and grouped in order to aid the development of the theory. Quotes from participants were integrated into the narrative of this study, selected to illustrate and represent the experiences of participants and the emergent theory (Anderson, 2010).

## **Results**

Four overarching themes emerged: understanding resilience, shared resilience, developing resilience, and factors that maintain resilience in dementia. Understanding

resilience provides an overview of how couples explained their resilience, shared resilience relates to the relationship that the couple had and how this impacted upon the development and maintenance of their individual and shared resilience. Developing resilience encapsulates the ways in which couples formed their resilience individually and together and factors that maintain resilience in dementia considers the resources that couples utilised in order to maintain and develop further resilience. Each theme is described with illustrative quotes from interviews and an emergent theory is then presented to describe the development and maintenance of shared resilience. This provides an explanation for how each of the themes inter-relate.

## **Understanding Resilience**

Participants initially struggled to define resilience, with one caregiver stating "I don't know really, what exactly does resilience mean?" (Mrs Smith – caregiver) whilst Mr Taylor described it as "the 'in' word that's come from somewhere" (Mr Taylor – PLwD). Difficulties in definition appeared to stem in part from the construct being so deeply embedded in everyday life. The majority of couples framed resilience in terms of the importance of being able to continue living the life they had before the dementia, doing things they had done before receiving the diagnosis, both individually and together. For couples, continuing activities together confirmed that they were coping as they were able to "just lead a normal life" (Mr Jones – PLwD) enabling them to "keep a hold on, the the sort of life that we used to have, the values of that life, erm and not let dementia win" (Mrs Evans – caregiver). Couples felt that failing to do this would impact negatively on their well-being. Resilience and well-being often felt enmeshed, with some couples struggling to differentiate between the two of them. An example of this is Mrs Evans who stated "I'd assumed that we're, we are talking or were talking all

the time about our happiness as a couple, cos I think, we're saying we've got plenty of resilience, if we hadn't we wouldn't be very happy" (Mrs Evans – caregiver).

Two perspectives that couples described in relation to their resilience and dementia was to remain positive and/ or to fight the dementia. Remaining positive was not a shared attitude help within the couple but instead was maintained independently from each other with one caregiver stating "I'm a great believer in looking on the bright side of things" (Mrs Brown – caregiver). However, consideration was given within interviews as to whether they were able to remain positive because their symptoms of dementia were still relatively mild; "Today's meeting has been very good, but... it has been able to be positive because the symptoms haven't developed much" (Mr Evans – PLwD). Another perspective which couples took was fighting the dementia which was shared between the couple, as Mrs Roberts explained "fighting against it, condition (dementia), fighting against what its making him into sort of thing, and making our lives" (Mrs Roberts – caregiver).

#### Shared resilience

A theme of resilient togetherness dominated all the interviews; this appeared key for their relationship and the maintenance of resilience, as Mrs Evans stated "there is an absolute determination that dementia is not going to come between us" (Mrs Evans – caregiver). Couples felt as though they had grown closer since the dementia, with one caregiver stating that they "are now more of a couple than 2 individuals getting on with life" (Mrs Roberts – caregiver), whilst another caregiver spoke about how they now "live more harmoniously than we did before" (Mr Edwards – caregiver). Couples spoke at length about how their relationship enabled them to develop and maintain resilience, but also their resilience improved the quality of their relationship enabling them to continue living the same kind of life; "resilience is trying to strengthen our relationship

if possible and it's something that I've been doing... so that we can continue to live together through this diagnosis" (Mr Edwards – caregiver). Throughout the interviews the terms resilience and relationship were used synonymously. This integration of resilience and relationship provides evidence for the importance of a couples' relationship within shared resilience. Therefore, the maintenance of their relationship is vital for couples to continue living a normal life despite facing the adversities associated with dementia.

For some, time spent in the relationship was important for the development of shared resilience, with a caregiver stating "we've been together nearly 50 years, would I feel like this if I'd only been together 7,8,10?" (Mrs Jones – caregiver). For others it was more about the quality of relationship that they had, as the Williams' who had been in a relationship for 10 years, the shortest amount of time in comparison to the other couples interviewed, disagreed stating, "we're comfortable, if we'd have been for 50 years we couldn't be more comfortable with each other" (Ms Williams – caregiver).

Another important factor in the maintenance of shared resilience for the couple was demonstrating and sharing acts of love, with a caregiver stating "when things get a bit rough we give each other a kiss, it's amazing how er how that helps" (Mrs Evans – caregiver). Another caregiver mentioned that she appreciated her husband buying her flowers every week, despite his age, dementia and arthritis.

A further way in which shared resilience was maintained was by talking together about the dementia, talking through and solving the problems they faced. However, discussion about the dementia had to be limited, with a PLwD stating that they "don't talk about it every day" (Mrs Edwards –PLwD). Not talking about dementia every day allowed priorities to be given to other things in their life, giving them a break and respite from the dementia. It may also be that couples chose not to talk about their dementia due to

cohort effects of sharing worries and concerns in addition to discourses around what it means to be diagnosed with dementia.

For both members of the couple retaining a sense of independence within the relationship was important in providing respite and an opportunity for both to recharge their batteries. For PLwD it was important that their diagnosis did not negatively impact on their partner, with one person saying "I don't hold her back from doing things" (Mr Brown – PLwD). By doing this it was hoped that their relationship would be able to continue in the same positive way, as Mr Taylor explained not doing so "would destroy her anyway and destroy our relationship" (Mr Taylor – PLwD).

#### **Developing resilience**

When seeking to explore where couples' resilience came from, responses varied widely both within and between couples. Some felt their resilience was part of who they were as individuals and therefore a personality trait, with one person stating "if you're that way inclined I think it goes straight through your life" (Mr Green – PLwD). Others felt that their resilience developed due to previous experiences including adversities they faced during childhood, for example growing up in the Second World War. This was corroborated by the Woods when asked where they had developed their resilience from, to which they responded "I think the start of your life" (Mrs Wood – PLwD). These early experiences enabled individuals to develop the fighting perspective couples described as being important in facing adversities associated with dementia; "we've had to face up to problems in life like that and that's the approach" (Mr Wood – caregiver). Others spoke about shared difficult experiences since being in a relationship together and the impact this had on their shared resilience.

Resilience was experienced as growing over time with age and also directly in response to living with dementia, with Mrs Taylor stating "maybe it's just something that we've learnt as we've gone on ... I think it probably has grown over the years" (Mrs Taylor – caregiver). This demonstrates that there is not an optimum level of resilience to reach, with the development of resilience described as more of a continual process, whereby the experiences and adversities that couples faced enable them to develop further resilience. Couples also continued to develop resilience as a result of the dementia diagnosis, with a caregiver stating "as a result of the diagnosis and that increased dependence on each of us erm, I think that has strengthened the relationship and provided that resilience" (Mr Edwards – caregiver).

Some couples stated that over the years, they have not always been resilient, with their resilience varying depending on "what you've got to cope with erm and as to whether then you can be resilient enough to cope with it" (Mr Taylor – PLwD). It was important for couples to accept that "you can't be strong all of the time" (Mrs Green – caregiver), and noting that "sometimes you just feel knocked down and vulnerable, and I think you've just got to accept that" (Mrs Green – caregiver).

#### **Factors that Maintain Resilience in Dementia**

Factors drawn upon to maintain resilience fell into two subthemes; the support which couples utilised and their ability to manage the dementia as a couple.

## Support

The support of others around the couple was imperative to be able to continue, as a caregiver stated "you need people, you need family or someone who cares" (Ms Williams – caregiver). People providing support included family (talking about their daughter); "she's been very supportive because she comes round and you know she

makes sure that we're alright and everything" (Mr Roberts – PLwD), friends; "I can't express enough about friends, you need... you must have a decent base of friends" (Mr Smith – PLwD), neighbours; "the neighbours are very good, and if anything was wrong they're here" (Mrs Brown – caregiver) and even pets; "I'd be totally lost without my dogs, I couldn't be without one" (Mrs Thompson - caregiver). However, couples highlighted the importance of also not becoming too reliant on others, with one caregiver stating "you just rely on each other and you just get on with it, don't you, you don't rely on anybody else" (Mrs Davies – caregiver).

Couples also valued the support of professionals, enabling the maintenance of resilience. This included healthcare professionals from whom couples valued consistency and working together which Mr Evans stated was beneficial as "consequently I think there isn't anything that we experience we wouldn't tell him is there?" (Mr Evans – PLwD). Other couples sought support from dementia support groups, enabling PLwD in the dyad to meet other people, learn about dementia, providing a routine for the couple and a different perspective on life with dementia. As an illustration, one PLwD stated: "what's wrong with any of us? We just have bad memories sometimes" (Mrs Edwards – PLwD). However, dementia support groups were not attended by all, as one caregiver stated it was "people just moaning" (Mrs Taylor – caregiver), and also PLwD reportedly worrying that it showed what the future might hold for them, "he doesn't want to go, because there will be people there with advanced dementia" (Mrs Davies – caregiver).

#### Managing the dementia

For many, in order to be able to manage the dementia, the first stage was to 'accept' their new life with a diagnosis of dementia; "I think you've got to accept it first, and then you go to... that's the first step, then you've got another step then... then you go on

from that one" (Mrs Jones – caregiver). This enabled couples to prepare for the future by having practical assurances in place such as a lasting power of attorney or making adaptations where necessary.

Couples spoke about the importance of making adaptations to their lives in order to maintain a similar kind of life as before. Adaptations included alterations to their houses, such as a walk-in shower, as well as adaptations to roles, such as the caregiver taking over the driving responsibility enabling the couple to continue socialising. This also included taking medication perceived to manage symptoms of dementia, as well as gaining information as "such knowledge makes it possible to do something about it" (Mr Evans – PLwD).

For PLwD being able to maintain things that they did as individuals before dementia was important. For example, Mr Smith stated "maintaining what I've been used to doing, all be it not as well, is still very important to me" (Mr Smith – PLwD).

Participants also emphasised the importance of doing new things such as going on holiday to new countries as expressions of a sustained sense of resilience. This enabled couples to prioritise other things over the dementia, ensuring that "Alzheimer's is something that is a shadow" (Mr Edwards – caregiver). Together couples actively attempted to shift the perspective on dementia and relegate it to the background in terms of their values, priorities and goals.

Humour was also utilised by couples to help manage adversities associated with dementia, with couples noting "there's always been a sense of humour" (Mr Williams – PLwD). As an example of a couples' use of humour, one PLwD described how he struggles with word finding but the response of the couple was to say "where did that come from? And we just laugh" (Mrs Thompson – caregiver).

Couples also compared themselves to others in a less fortunate position than themselves, such as those with cancer, those who had been diagnosed with dementia at a younger age or those diagnosed with dementia at an older age; "when you're a bit younger, perhaps you have that bit of a more wider horizon in front of you" (Mr Davies – PLwD).

Finally, financial stability was helpful for couples to manage dementia enabling them to afford to make adaptations to their homes and go on holidays to give themselves a break. Having financial stability also provided couples with peace of mind that should the PLwD need to go into a care home, they would be able to afford one which felt like home. For other couples, the benefits of finances were less about affording the luxuries and more about affording the basics, with a caregiver stating "if I was cold or uncomfortable or hungry all the time I'd be in a bad temper" (Ms Williams – caregiver).

## **Emergent Theory**

Figure 3 illustrates an emergent grounded theory of shared resilience in couples living with dementia. It highlights the importance of a sense of shared resilience between dyads, and how shared resilience can continue to grow and develop throughout life. Couples spoke about their relationship and shared resilience interchangeably, suggesting that the relationship of the dyad is imperative for shared resilience. Couples utilise two perspectives to remain resilient; positivity and fighting the dementia. The resilience shared between the dyad enabled couples to maintain and develop their own individual resilience, whilst the development and maintenance of such resilience helped develop and grow their shared resilience. This created a reciprocal and open ended relationship between their shared resilience and the development and maintenance of their own individual resilience. This process resulted in the continual development of

resilience throughout the couples' lives and journey through dementia, enabling them to meet the challenges of dementia and continue living a normal life. Couples did not describe themselves as consistently resilient, with levels of resilience varying dependent on the amount they had to cope with on a day-to-day basis. In this instance it was important to acknowledge and accept this, leading to the eventual recovery of their resilience and further development of shared resilience. This suggests that shared resilience ebbs and flows, growing and developing throughout life, in spite of and because of dementia, enabling dyads to continue living a normal life, despite the adversity of the dementia diagnosis.

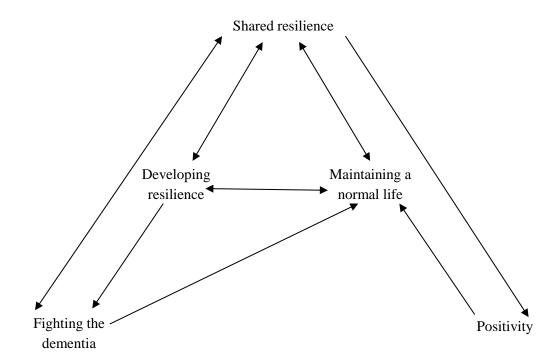


Figure 3. An emergent theory of resilience in couples living with dementia

## **Discussion**

This study is novel in its exploration of resilience in the lives of couples living with dementia. A central finding within the study is the importance of the relationship in maintaining and developing shared resilience, providing insight into the needs of both caregivers and PLwD (Ryan, et al., 2008) and the relational aspects of dementia

(Daniels et al., 2007; Molyneaux, et al., 2012). The emergent theory suggests the importance of couplehood in sustaining and developing resilience whilst living with dementia. When couples in the present study considered their shared sense of resilience they intuitively drew upon their sense of couplehood and the shared strategies they were using to continue to lead what they considered to be a 'normal life'. Therefore, interventions aimed at building resilience should engage couples together to consider how a couple's shared resilience can be improved. These findings reflect family resilience, in which the relationship of the family is vital for the development of a shared sense of resilience between its members (Walsh, 2011). The relationship of the dyad has also been found to be vital for shared resilience within cancer survivors (Lim, Shon, Paek & Daly, 2014); a meta-analysis concluded that dyadic coping can improve relationship functioning in couples living with cancer (Traa, De Vries, Bodenmann & Oudsten, 2015).

An aim of the study was to develop an understanding of what resilience meant to couples living with dementia. However, perhaps understandably, couples often found it difficult to define. This is consistent with previous research that asked caregivers of PLwD about resilience (O'Dwyer et al., 2017). Yet despite the difficulties defining resilience all couples were able to talk about what it meant to them and how it had been experienced, describing it as their ability to continue living a normal life. This view of 'everyday resilience' diverges somewhat from the three definitions proposed by Lepore and Revenson (2006): 'resistant resilience', 'recovery resilience', and 'reconfiguration resilience', and other research which suggests that resilience is about flourishing (Bekhet & Avery, 2018). Instead, this definition aligns more closely with Windle and Bennett's (2011) definition that resilience in later life is most closely tied with the perceived maintenance of functioning. Findings from this research concur with the idea that resilience is an 'ordinary magic' (Masten, 2001), in which people adapt and change

to cope with the difficulties they are faced with. Findings therefore provide an alternative perspective from which resilience can be understood in dementia. This definition would assume that many people are able to develop and maintain resilience and so the way in which resilience is measured within dementia will need to be reconsidered.

Couples took two different perspectives in order to maintain a normal life in the face of dementia: positivity and fighting. This reflects Clare's (2002) finding that people adjust to early stage dementia by developing a 'fighting spirit', in which they face the threats of dementia head on, alongside 'holding on' and compensating trying to preserve their sense of self. Whilst Clare's (2002) study focused on individuals in the early stage of Alzheimer's dementia, the current study considers the views of dyads in both the early and mid-stages of dementia. This suggests therefore, that the perspectives of positivity and fighting the dementia can not only be maintained throughout the journey of dementia when the symptoms become more severe, but also can be held together as a couple. Within the current study most couples utilised both perspectives flexibly in order to maintain a normal life. However, older couples and those further in their diagnosis tended to focus on remaining positive rather than maintaining a fighting spirit, possibly due to it becoming harder to fight the dementia as it progresses further. In addition to this it may be that remaining positive becomes an important way to experience positive emotions whilst also preserving a sense of mutuality in relationships (i.e. staying positive together) as dementia progresses. It is important to note that it has been suggested that the use of military metaphors such as fighting, within healthcare can help raise awareness and fundraising (Lane, McLachlan & Philip, 2013). However, it has been argued that these metaphors are unhelpful within dementia, as there are no curative treatments available, which may lead people to feeling as though they have lost their battle with dementia (Lane et al., 2013).

The finding that resilience is experienced as developing over time resonates with other perspectives of resilience which propose a cyclical process as opposed to a trait which people either do or do not possess (Jacelon, 1997). This was also found in resilience research with dementia caregivers (O'Dwyer et al., 2017). The emergent theory therefore presents the development and maintenance of shared and individual resilience as a cyclical process, something which Windle and Bennett's (2011) framework has been criticised for in its use with dementia caregivers (O'Dwyer et al., 2017). Despite this critique, the resources enabling shared resilience found within this study could be divided into the individual, community and society resources which Windle and Bennett (2011) outline within their framework. Findings from this study therefore provide evidence that couples living with dementia utilise similar resources to remain resilient as caregivers of older adults do.

A critique of the Windle and Bennett (2011) framework is that it is reductionist, predefining specific factors and resources from which people draw upon to be resilient (O'Dwyer et al., 2017). Research in dementia suggests that resilience is subjective, complex and multidimensional (Donnellan et al., 2015). Therefore, whilst this research presents findings and a theory specific to the sample this is not a definitive account of factors which develop and maintain resilience in couples living with dementia. This is due to the complexity of resilience in which factors would vary dependent upon the couple. For example, for some couples support groups were a vital mechanism to facilitate resilience, whilst for others support groups would create worry about the future and hinder resilience. Findings therefore suggest that couples take different potential pathways in order to develop and maintain a shared sense of resilience, in addition to utilising common underpinning resources and processes.

#### Limitations

The researcher purposively sampled participants through a number of recruitment methods, in order to reach data and theoretical saturation, however, it could be argued that a limitation of the study was the lack of diversity amongst participants. When considering diversity, it can be helpful to utilise a framework in which the diversity of participants can be reflected upon, such as Burnham's social graces model (2012). The social graces framework is multifaceted and considers a wide range of characteristics. Some of the characteristics in which the research was considered to be lacking in diversity includes gender, geography, race, ethnicity and sexual orientation. When considering gender, the majority of caregivers involved in the study were female, whilst the majority of PLwD were male. Research has found there are gender differences in the experience of providing care for PLwD (Pinquart and Sörensen, 2006), therefore future research should attempt to have a balance between the gender of caregivers and PLwD. Couples were also recruited from a small regional area of the UK, Yorkshire, with all of the participants identifying as White British, indicating a lack of diversity in geography, race and ethnicity. Finally in relation to sexual orientation, each of the couples interviewed were in heterosexual relationships. McParland and Camic (2018) found that dementia is experienced differently in same sex couples, therefore, future research should endeavour to include same sex romantic relationships. Participants were not asked about a number of the areas of the social graces model including religion, education, employment or spirituality, therefore the diversity or lack of diversity amongst participants within these areas of the social graces model cannot be commented on.

In addition to limitations of diversity, this research only offers an insight into shared resilience within romantic relationships. There are a number of caregiving relationships

in which shared resilience may be developed and maintained, such as parental and sibling relationships or friendships. Future research could therefore consider how other relationships may foster resilience in dementia.

During the interviews couples reflected on whether, as they continue through the journey of dementia, their resilience will change. Resilience research could therefore benefit from either being longitudinal to understand how a shared sense of resilience might change over time or include couples whos symptoms of dementia are more severe.

This research provides a detailed understanding of the experience of resilience in dementia, but does not focus on how resilience can be developed in couples who do not consider themselves to be resilient. Future research which considers how resilience can be developed may be useful for resilience interventions in couples living with dementia.

Despite these limitations, this study is novel in its exploration of the experience of shared resilience in dementia. Findings provide an alternative perspective of resilience in dementia and emphasises the importance of dyadic research to enable further insight into the experience of living well with dementia. This study also provides evidence for the complex and multidimensional nature of resilience, highlighting that what may facilitate resilience in some, may hinder resilience in others. Furthermore, the emergent theory highlights the importance of couplehood whilst living with dementia, enabling couples to develop a shared sense of resilience and ultimately maintain a 'normal' life. Finally, this study proposes an alternative perspective from which resilience can be understood, defining shared resilience as continuing with normal life. This definition fits better with the idea that resilience is an 'ordinary magic' (Masten, 2001). Such findings may affect how resilience is measured within dementia, as this definition

would assume that many people are able to develop and maintain resilience, and ultimately "live well with dementia".

# **Declaration of conflicting interests**

The authors declare that there is no conflict of interest.

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**Part Three: Appendices** 

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# **Appendix B: Mixed Methods Appraisal Tool**

#### PART II. MMAT tutorial

Types of mixed methods study components	Methodological quality criteria
or primary studies	
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?
Common types of qualitative research methodology include:	
A. Ethnography The aim of the study is to describe and interpret the shared cultural	E.g., consider whether (a) the selection of the participants is clear, and appropriate to collect relevant and rich data; and (b) reasons why certain potential participants chose not to participate are explained.
behaviour of a group of individuals.	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?
B. Phenomenology The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals.	E.g., consider whether (a) the method of data collection is clear (in depth interviews and/or group interviews, and/or observations and/or documentary sources); (b) the form of the data is clear (tape recording, video material, and/or field notes for instance); (c) changes are explained when methods are altered during the study; and (d) the qualitative data analysis addresses the question.
C. Narrative The study analyzes life experiences of an individual or a group.	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?*
D. Grounded theory Generation of theory from data in the process of conducting research (data collection occurs first).	E.g., consider whether the study context and how findings relate to the context or characteristics of the context are explained (how findings are influenced by or influence the context). "For example, a researcher wishing to observe care in an acute hospital around the clock may not be able to study more than one hospital. () Here, it is essential to take care to describe the context and particulars of the case [the hospital] and to flag up for the reader the similarities and differences between the case and other settings of the same type" (Mays & Pope, 1995).
E. Case study In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making	The notion of context may be conceived in different ways depending on the approach (methodology) tradition.
process, to a person, an organization, or a country.	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants? *
F. Qualitative description	Financial
There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic analysis (inductive and deductive).  Key references: Creswell, 1998; Schwandt, 2001; Sandelowski, 2010.	E.g., consider whether (a) researchers critically explain how findings relate to their perspective, role, and interactions with participants (how the research process is influenced by or influences the researcher); (b) researcher's role is influential at all stages (formulation of a research question, data collection, data analysis and interpretation of findings); and (c) researchers explain their reaction to critical events that occurred during the study.
Rey ferences. Creswen, 1770, Schwand, 2001, Sandelowski, 2010.	The notion of reflexivity may be conceived in different ways depending on the approach (methodology) tradition. E.g., "at a minimum, researchers employing a generic approach [qualitative description] must explicitly identify their disciplinary affiliation, what brought them to the question, and the assumptions they make about the topic of interest" (Caelli, Ray & Mill, 2003, p. 5).

<sup>\*</sup>See suggestion on the MMAT wiki homepage (under '2011 version'): Independent reviewers can establish a common understanding of these two items prior to beginning the critical appraisal.

Types of mixed methods study components or primary studies	Methodological quality criteria
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?
Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers).	In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance, and researchers describe how the randomization schedule is generated. "A simple statement such as 'we randomly allocated' or 'using a randomized design' is insufficient".
	Simple randomization: Allocation of participants to groups by chance by following a predetermined plan/sequence. "Usually it is achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer".
Key references: Higgins & Green, 2008; Porta, 2008; Oxford Center for Evidence based medicine, 2009.	Sequence generation: "The rule for allocating interventions to participants must be specified, based on some chance (random) process". Researchers provide sufficient detail to allow a readers' appraisal of whether it produces comparable groups. E.g., blocked randomization (to ensure particular allocation ratios to the intervention groups), or stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics).
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?
	The allocation concealment protects assignment sequence until allocation. E.g., researchers and participants are unaware of the assignment sequence up to the point of allocation. E.g., group assignment is concealed in opaque envelops until allocation.
	The blinding protects assignment sequence after allocation. E.g., researchers and/or participants are unaware of the group a participant is allocated to during the course of the study.
	2.3. Are there complete outcome data (80% or above)?
	E.g., almost all the participants contributed to almost all measures.
	2.4. Is there low withdrawal/drop-out (below 20%)?
	E.g., almost all the participants completed the study.

Types of mixed methods study components or primary studies	Methodological quality criteria
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?
Common types of design include (A) non-randomized controlled trials, and (B-C-D) observational analytic study or component where the intervention/exposure is defined/assessed, but not assigned by researchers.	At recruitment stage:  For cohort studies, e.g., consider whether the exposed (or with intervention) and non-exposed (or without intervention) groups are recruited from the same population.
A. Non-randomized controlled trials  The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups.	For case-control studies, e.g., consider whether same inclusion and exclusion criteria were applied to cases and controls, and whether recruitment was done independently of the intervention or exposure status.  For cross-sectional analytic studies, e.g., consider whether the sample is representative of the population.
B. Cohort study Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal).	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?  At data collection stage:
corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective).  D. Cross-sectional analytic study	E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) the measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.
	For non-randomized controlled trials, the intervention is assigned by researchers, and so consider whether there was absence/presence of a contamination. E.g., the control group may be indirectly exposed to the intervention through family or community relationships.
of outcomes is compared in different population sub-groups according to the presence/absence (or level) of the intervention/exposure.	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?
Key references for observational analytic studies: Higgins & Green, 2008; Wells, Shea, O'Connell, Peterson, et al., 2009.	At data analysis stage:
	For cohort, case-control and cross-sectional, e.g., consider whether (a) the most important factors are taken into account in the analysis; (b) a table lists key demographic information comparing both groups, and there are no obvious dissimilarities between groups that may account for any differences in outcomes, or dissimilarities are taken into account in the analysis.
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?

Types of mixed methods study components	Methodological quality criteria
or primary studies	
4. Quantitative descriptive studies	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?
Common types of design include single-group studies:	
A. Incidence or prevalence study without comparison group  In a defined population at one particular time, what is happening in a population, e.g.,	E.g., consider whether (a) the source of sample is relevant to the population under study; (b) when appropriate, there is a standard procedure for sampling, and the sample size is justified (using power calculation for instance).
frequencies of factors (importance of problems), is described (portrayed).	4.2. Is the sample representative of the population understudy?
B. Case series A collection of individuals with similar characteristics are used to describe an outcome.	E.g., consider whether (a) inclusion and exclusion criteria are explained; and (b) reasons why certain eligible individuals chose not to participate are explained.  4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?
C. Case report	4.5. Are measurements appropriate (clear origin, or valuity known, or standard instrument):
An individual or a group with a unique/unusual outcome is described in details.  Key references: Critical Appraisal Skills Programme, 2009; Draugalis, Coons & Plaza, 2008.	E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.
	4.4. Is there an acceptable response rate (60% or above)?
	The response rate is not pertinent for case series and case report. E.g., there is no expectation that a case series would include all patients in a similar situation.

Types of mixed methods study components	Methodological quality criteria
or primary studies	
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research
Common types of design include:	questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?
A. Sequential explanatory design     The quantitative component is followed by the qualitative. The purpose is to explain quantitative results using qualitative findings. E.g., the quantitative results guide the selection	E.g., the rationale for integrating qualitative and quantitative methods to answer the research question is explained.
of qualitative data sources and data collection, and the qualitative findings contribute to the interpretation of quantitative results.	5.2. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?
B. Sequential exploratory design  The qualitative component is followed by the quantitative. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the qualitative findings inform the quantitative data collection, and the quantitative results allow a generalization of the qualitative findings.	E.g., there is evidence that data gathered by both research methods was brought together to form a complete picture, and answer the research question; authors explain when integration occurred (during the data collection-analysis or/and during the interpretation of qualitative and quantitative results); they explain how integration occurred and who participated in this integration.
C. Triangulation design  The qualitative and quantitative components are concomitant. The purpose is to examine the same phenomenon by interpreting qualitative and quantitative results (bringing data analysis together at the interpretation stage), or by integrating qualitative and quantitative datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data).	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results)?
D. Embedded design The qualitative and quantitative components are concomitant. The purpose is to support a qualitative study with a quantitative sub-study (measures), or to better understand a specific issue of a quantitative study using a qualitative sub-study, e.g., the efficacy or the implementation of an intervention based on the views of participants.	
Key references: Creswell & Plano Clark, 2007; O'Cathain, 2010.	

# **Appendix C: Data Extraction Tool**

Title, Author, Date and Location	
Aims of the Study	
Sample and recruitment	
Design and Methodology	
Findings	
Definition of resilience	
Dyadic Perspective	

# **Appendix D: Methodological Quality Summary Table**

Types of study components of primary studies	Methodological Quality criteria	Bekhet and Avery (2018)	Bull (2014)	Deist and Greeff (2015)	Deist and Greeff (2017)	Donnellan, et al. (2015)	Donnellan, et al. (2017)	Harris (2008)	O'Dwyer et al. (2017)	Williamson and Paslawski (2016)	Wong et al. (2015)
Screening	Are there clear research questions or objectives?	1	1	1	1	1	1	1	1	1	1
questions (all)	Does the collected data address the research questions or objectives?	1	1	1	1	1	1	1	0	1	1
	Are sources relevant to address the research question?	1	1	1	1	1	1	1	1	1	1
Qualitative	Is the process of analysing relevant to the research question?	1	1	1	1	1	1	1	1	1	1
Quantative	Is consideration given to how findings relate to context?	0	0	1	1	1	1	0	1	1	1
	Is consideration given to how findings relate to researcher influence?	1	0	0	0	1	0	1	0	0	0
	Is there a clear description of randomisation?										
Quantitative	Is there a clear description of the allocation concealment?										
(RCTs)	Are there complete outcome data (>80%)?										
	Is there a low drop-out (<20%)										
	Are participants recruited to minimise selection bias?										
Quantitative (non- randomised)	Are measures appropriate?										
	Are measurements appropriate regarding intervention and outcomes?										
	Are there complete outcomes data (>80%), acceptable response rate (>60%) or an acceptable follow up rate?										

	Is the sampling strategy relevant to address the research question?		1	0	0						
Quantitative descriptive	Is the sampling representative?		1	1	1						
descriptive	Are measurements appropriate?		1	1	1						
	Is there an acceptable response rate (>60%)?		1	0	0						
	Is the mixed methods design relevant to address the qual and quan research questions?		1	1	1						
Mixed Methods	Is the integration of results relevant to the research question?		1	1	1						
	Is appropriate consideration given to limitations with the integration?		1	0	0						
	Total	83%	85%	75%	83%	100%	83%	83%	67%	83%	83%

# <u>Key</u>

Score of 1 = Yes

Score of 0 = No or unsure

#### **Appendix E: Instructions for Contributors to the Journal 'Dementia'**

This Journal is a member of the Committee on Publication Ethics.

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/dementia to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Dementia will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

- 1. What do we publish?
  - 1.1 Aims & Scope
  - 1.2 Article types
  - 1.3 Writing your paper
- 2. Editorial policies
  - 2.1 Peer review policy
  - 2.2 Authorship
  - 2.3 Acknowledgements

- 2.4 Funding
- 2.5 Declaration of conflicting interests
- 2.6 Research ethics and patient consent
- 3. Publishing policies
  - 3.1 Publication ethics
  - 3.2 Contributor's publishing agreement
  - 3.3 Open access and author archiving
- 4. Preparing your manuscript
  - 4.1 Formatting
  - 4.2 Artwork, figures and other graphics
  - 4.3 Supplementary material
  - 4.4 Reference style
  - 4.5 English language editing services
- 5. Submitting your manuscript
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  - 5.2 Information required for completing your submission
  - 5.3 Permissions
- 6. On acceptance and publication
  - **6.1 SAGE Production**
  - 6.2 Online First publication
  - 6.3 Access to your published article
  - 6.4 Promoting your article
- 7. Further information

#### 1. What do we publish?

#### 1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

## 1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 2,500-3,000 words. Innovative practice papers should include the words 'Innovative Practice' after the title of their article when submitting to the journal. For further information about innovative practice papers, please refer to the guidelines.

The journal also publishes book reviews.

#### 1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

#### 1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your

abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

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#### 2. Editorial policies

#### 2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.
   Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

#### 2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved,

regardless of their status. A student is usually listed as principal author on any multipleauthored publication that substantially derives from the student's dissertation or thesis.

#### 2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

#### 2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

#### 2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

#### 2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal. Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

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#### 3. Publishing Policies

#### 3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

#### 3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

### 3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

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#### 3.3 Open access and author archiving

Dementia offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

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#### 4. Preparing your manuscript for submission

#### 4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

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For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

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colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

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This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

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#### 4.5 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

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#### 5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne<sup>TM</sup> Manuscripts.

Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past

year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty jo.moriarty@kcl.ac.uk. Books for review should be sent to: Book Review Editor, Dementia, Caroline Swarbrick University of Manchester, UK caroline.swarbrick@manchester.ac.uk

#### 5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities ensuring that their work is recognised.

We encourage all authors to add their ORCIDs to their SAGE Track accounts and include their ORCIDs as part of the submission process. If you don't already have one you can create one here.

#### 5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

#### **5.3 Permissions**

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

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#### 6. On acceptance and publication

#### **6.1 SAGE Production**

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

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Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

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#### 7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Appendix F: Documentation of Research Ethics Committee Approval
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Appendix G: Documentation of Health Research Authority Approval			
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#### **Appendix H: Research Poster**









## **VOLUNTEERS NEEDED!**

# Exploring shared experiences of resilience in people with dementia and their partners

#### Who can take part?

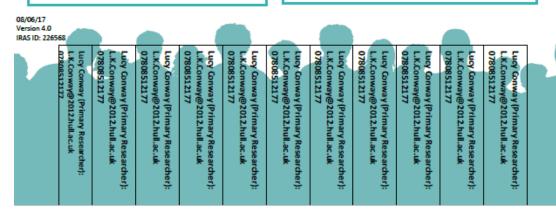
We are looking for couples living together where one person is over 65 and has dementia and the other person is their partner



You will be asked to attend an interview to talk about the challenges and changes you have faced as a couple since living with dementia. The interview will be done with you and your partner together at a time and place that suits you. It will last approximately 1 hour



If you would like to
participate or would like
more information, please
contact Lucy Conway
(Trainee Clinical
Psychologist)
L.K.Conway@2012.hull.ac.uk
/ 07808512177 for more
details



#### **Appendix I: Participant Information Sheet**

#### **Participant Information Sheet**

**Project Title:** Exploring shared experiences of resilience in people with dementia and their partners

**Invitation:** I would like to invite you both to take part in a research study looking at how couples respond to the challenges and changes of dementia. Before deciding whether you would like to take part I would like you to read through this information sheet to understand why the research is being done and what it involves. Please can you read the information carefully before making your decision as to whether you would both like to be involved. Please ask me any question that you might have.

**Purpose of this study:** This study is looking at resilience. The word 'resilience' can be hard to explain and people think about it in different ways. Some people understand resilience to mean 'bouncing back' from problems, whilst others think it could be about staying strong when times get tough. Living with dementia can bring challenges and changes for people with dementia and their partners, and we want to learn more about these experiences. Therefore, this study hopes to gain an understanding of couples' experiences of living with the challenges and changes of dementia, what resilience means to them, how couples get along together and how they feel about life.

Why have you been invited to take part?: You have both been invited to take part in this research as a couple because either you are over 65 and have a diagnosis of dementia or because you are the spouse or partner of a person with a diagnosis of dementia. This information sheet has been given to you as a couple because you may be interested in taking part in this study together.

**Do we have to take part?** No. Participation is voluntary and it is up to both of you to decide to join this study. As we are interested in talking to both of you about your experiences, it is important that as a couple you are both interested in taking part in this study together. If you decide to take part but later change your mind, it's fine to stop the study and no longer be a part of it. You will both be free to withdraw from this study up to the point where the results are analysed and written up and if you would like to withdraw, you do not have to give a reason for this. Deciding not to do the study will not affect the care you get or your legal rights.

What will happen if we decide to take part? You will be asked to give your contact details so that the researcher can get in contact with you to arrange a time and place to sit down with you both and ask some questions together, and also feedback the results to you after the research has finished. These details will include your name, address, phone number and email address. The interview will be relaxed and informal and can take place at a time and place suitable for you, either face to face, for example at your home, over Skype or alternatively over the phone. During this interview, you will both be asked to talk about your experiences of challenges and changes since receiving the diagnosis of dementia, how you get along together and how you feel about life. You will also be asked to provide some brief information about yourselves including your age, how long you have been in your relationship, the diagnosis of dementia and the time since this diagnosis was given, as well as some other things. This interview will take approximately 1 hour.

What are the benefits and risks of taking part?: Whilst it is unlikely that there will be any direct benefits to you as a couple, being involved in the study may improve knowledge about dementia and also provide ideas for support for couples living with dementia, such as the support that people with dementia and their families could receive.

It is not expected that this study will involve any risks or cause you distress but if at any time either of you feel upset you will be able to stop for a break or stop the interview altogether. This can be done up to the point where the results are being analysed. A list of contacts for support has been provided at the end of this information sheet with the details of places you can access support should you need it. The researcher will also be able to offer you support and can help you access further help and support from dementia support services if you need this.

What will happen if I decide I no longer wish to take part?: As we are interested in talking to both of you about your experiences, it is important that as a couple you are both interested in taking part in this study together. Therefore, if one member of the couple decides that they no longer wish to take part in the study, then the interview will be stopped and information gathered from the interview will not be included in the analysis stage of this study. Deciding that you no longer want to be involved in the study will not affect the care you get or your legal rights. You can choose to withdraw from this study up to the point where the results are being analysed.

Anonymity and Confidentiality: Information collected from this study will be used for this study only and will not be used for any other purpose. If an NHS staff member has identified you as a potential participant, then your contact details will be given to the researcher to contact you to arrange an interview. These contact details will be kept securely, in a locked cabinet at the University of Hull or on a password-protected device which only the researcher has access to. These contact details will be kept for 3-6 months after the research has finished so that that researcher can feedback the results to you, should you wish. It is hoped that these findings will be fed back within 6 months of your involvement in this research. All other information collected from the interview will be kept separately from your contact details and will be anonymised, which means that you will not be identified by name at any point. Anonymised information will be stored securely for 10 years and will then be destroyed. We will follow ethical and legal practice and all information about you will be handled in confidence.

What will happen to the results of the study? The results of this study will be presented in a doctoral thesis, sent for publication in an academic journal and may be presented at conferences. Participants will not be identifiable in the final study reports or in any conference presentations.

Who is organising and funding the research? Lucy, the researcher carrying out this research is a student at the University of Hull and this research is being carried out as part of a doctorate level training program in clinical psychology, with the approval of Humber NHS Foundation Trust.

What if there is a problem? If you have concerns about any part of this study it may be helpful to discuss these with the researcher who will do their best to answer your questions. You could also get in contact with the researcher's supervisors at the

University of Hull. Finally, you can also contact the local NHS Patient and Advice and Liaison Service (PALS) on telephone number 01482 303 966 or via email: HNF\_TR.pals@nhs.uk.

Who has reviewed the study? Independent Research and Ethics Committees protect the interests of people who participate in research. This study has been reviewed by an NHS Research and Ethics Committee.

What should I do next? If both of you are interested in taking part in this research please complete the consent form, your contact details and preferred method of communication so that the researcher can feedback the findings from the study, should you wish. If you have any further questions, then please do not hesitate to ask.

#### For further information and support

Researcher: Lucy Conway 07808512177 l.k.conway@2012.hull.ac.uk

Research Supervisors: Dr Chris Clarke

01482 464106

c.clarke@hull.ac.uk

Dr Emma Wolverson 01482 464170

e.wolverson@hull.ac.uk

Address: Lucy Conway/ Chris Clarke/ Emma Wolverson

Department of Psychological Health and Wellbeing,

University of Hull, Cottingham Road,

Hull, HU6 7RX

#### **Sources of Support**

Should you require any support before, during or after taking part in this research, please find below a list of possible contacts for support.

If you feel that you need any support regarding the research please get in contact with the **researcher** on: **07808512177** 

Or the researcher's supervisors on: 01482 464106/ 01482 464170

The **Alzheimer's Society** offers support for both people with dementia and their caregivers and family. More information, and details of local branches can be found at:

#### https://www.alzheimers.org.uk/

Their National Dementia helpline can be called, offering information, support and advice about dementia:  $0300\ 222\ 11\ 22$ 

MIND are able to provide information and advice relating to types of mental health problems, where to get help, medication and alternative treatment and advocacy. They can be called on: 0300 123 3393

Or emailed at:

#### info@mind.org.uk

**Samaritans** offer free 24-hour confidential support, providing a non-judgemental label free service where callers are able to talk about their worries, concerns and difficulties with a trained professional. They can

be called on: 116 123

Or emailed at:

### jo@samaritans.org

Finally you can also seek advice from your GP or local NHS mental health service

#### **Appendix J: Consent Form**

#### **CONSENT FORM**

**Title of Project:** Exploring couples' experiences of shared resilience and its' relation to shared well-being and the relationships of couples living with dementia

Name of Researcher: Lucy	Conway	Please	initial boxes
30/06/2017 (Version 6.0)	ead and understand the inform for the above study. I have ha tion. If I had any questions,	d the opportunity	
withdraw at any time wit	participation is voluntary and shout giving any reason up to a, without my medical care or	the point of data	
3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.			
4. I agree to take part in the interview part of the study and understand that my interview will be audio recorded.			
Name of participant	Date	Signature	
Name of person taking consent	Date	Signature	

Please fill in this information if you would like to be contacted to discuss the findings of the research, this can be done face to face, via telephone or on Skype.

When completed: 1 for participant; 1 for researcher site file.

Name:		
Address:		
Telephone Number:		
Mobile Phone Number:		
Email Address:		
Preferred method of contact:		
Are there any times of the da	y that you prefer to be con-	tacted?
Preferred method of contact?	Please circle	
Face to Face	Telephone (loudspeaker)	Skype
	Signature:	
	Date:	

Thank you very much for your interest!

## Appendix K: Demographic Questionnaire

## **Demographic Questionnaire**

1.	What are both of your names and ages? Name of person with dementia: Name of caregiver:	Age: Age:		
2.	What ethnicity are you?			
	Person with dementia: Caregiver:			
3.	How long have you been in your relationship for?			
4.	What is you diagnosis of dementia (if known)?			
	Can you tell me roughly when you got your diagnosis opesn't need to be exact?	f dementia- this		
6.	Would you define yourself as's main informal ca	aregiver? If not why?		

#### **Appendix L: Semi-structured Interview Schedule**

The following questions provide a schedule for the interview questions. Due to using Constructivist Grounded Theory further questions were added in order to help clarify and fill gaps in the emergent theory. Questions added to fill in gaps in emergent theory are in italics.

#### **Introductory Statement:**

When someone receives a diagnosis of dementia it can be very upsetting for both the person who has received the diagnosis and their loved ones around them. Despite this, some people with dementia and their loved ones are able to cope and adjust to life with dementia, which research has linked to resilience. This is something that I would like to talk to you both about today.

#### Meaning of Resilience:

So I was wondering if I could hear about what your understanding of resilience is?

- Prompt: What kind of words would you use to describe resilience?
- Prompt: Can you think of an example?

#### **Developing resilience**:

Where has your resilience come from?

• Prompt: Have you always [their definition of resilience?]

Has your resilience changed over time?

• Prompt: If we were to draw a graph of resilience and time, what would it look like?

What has helped your resilience to change over time?

#### **Maintaining Resilience:**

What helps you to [their definition of resilience]?

- Prompt: What do you need in your life to [their definition of resilience]?
- Prompt: Can you think of anything else that [their definition of resilience]?
- Prompt: So what kinds of things is it that [maintaining factor] does that helps you to [their definition of resilience]?
- Prompt: Why is it that [maintaining factor] helps you to [their definition of resilience]?

#### The impact on their relationship:

So how do you think your [their definition of resilience] has affected your relationship together?

Some couples have really struggled to answer this question – do you have any ideas why this might be?

#### The impact on their well-being:

So how do you think your [their definition of resilience] has affected your well-being together?

Some couples have really struggled to answer this question – do you have any ideas why this might be?

#### **Ending of interview:**

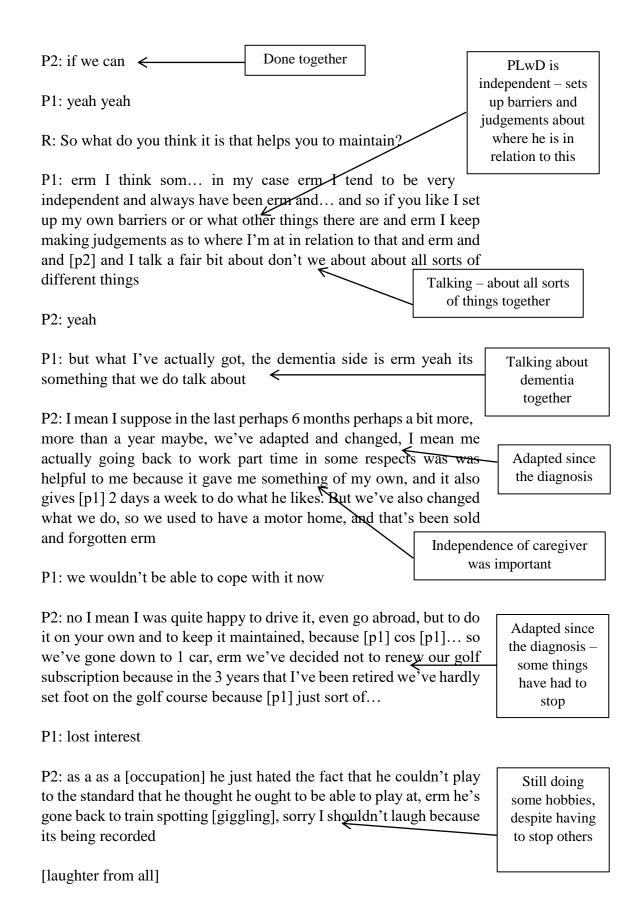
I have come to the end of my questions now, is there anything else you want to discuss?

#### Appendix M: Worked Example of Transcription Initial Coding

Worked example of the data extraction and focused coding from a transcript. R = researcher, P1 = PLwD, P2 = caregiver

R: My research interest is about resilience and in particular the resilience that you share together erm since being diagnosed with dementia, erm but a lot of the research talks about it in different ways Resilience is a so what I was wondering is if both of you could talk a little bit about buzzword what does resilience mean to you 2? does it have a meaning? P1: Is this the in word that's come from somewhere R: possibly Surviving Resilience is surviving and [laughter] coping with the dementia P1: erm, well for me resilience is, er it's to do with survival, I suppose of of, you're given information an.... That you have something, which I going to affect you I think dramatically, er and so er you need to be able er to cope with it erm and I suppose survive it really erm Survival and coping through the P2; mmm mmm, yes I suppose its what coping mechanisms, which progression of is another in phrase isn't it, it's the coping mechanisms that you use dementia to set up or maintain your resilience rather than... where as if you don't do anything perhaps you have zero resilience...that's... yeah Coping mechanisms P1: mmm yeah used P2: that's how I can, that's how I understand it, is how we cope with it or not P1: yeah Resilience is how they as a couple cope with it or not P2: yeah P1: on a day by day basis Coping day by day P2: mmm Few symptoms of dementia P1: yeah because er you have different things that will affect you by what I've got, er which at the moment erm hopefulfy I'm not showing, only part of it is showing, erm and that that needs to be, I don't know... Few symptoms are important to maintain for P2: maintained ← resilience?

P1: maintained



## **Appendix N: Example of Coding Process**

Quote	Initial Coding	<b>Focused Coding</b>	Theoretical Coding
"I think it would be very hard, if you didn't have that bond, and this is what I was going back to you, we've been together nearly 50 years, would I feel like this if I'd only been together 7,8,10 ?" (Mrs Jones – caregiver)	The bond in a relationship is important  Time spent in the relationship is important – 50 years builds the bond  Being together for a shorter period of time would change how they were able to be resilient	Time in relationship builds the bond and is important for resilience	9
"we are completely different in every single way, but we have this same mind set so that when these things are thrown at us we come, instead of going further apart we come together, and we've always been like that" (Mr Davies – PLwD)	They are both different  Having the same mind set is helpful  When faced with adversities they come together  This is something they have always done	When facing adversities coming together is important	Shared resilience
"you each have your own view of life in some respects er and maybe one or both of you have totally different interests, like me with my trains and whatever which [caregiver] doesn't get involved in, she just organises the holidays that included, includes trains. So	Each member of the couple has their own views of life which must be respected  Each member of the couple has their own interests which each other do not get involved in	Having independence from each other is important for resilience	

I think you have to get away from from like dementia and whatever, because you can't live with it every day, because it'll just, it just sits there!" (Mr Taylor – PLwD)	Having activities and interests enables you to get away from the dementia		
"we live the same kind of life even though the the dementia, er we're perfectly well aware will start the bite, that the important thing is to keep a hold on, the the sort of life that we used to have, the values of that life, erm and not let dementia win" (Mrs Evans – caregiver)	Living the same kind of life  Dementia will progress over time and they are aware of that  It is important to try and keep hold of the life they used to have before the diagnosis of dementia  This means not letting the dementia win	Resilience is about being able to live the same kind of life, despite the progression of the dementia  Maintaining a normal life	
"well I think my resilience is to carry on as normal as possible and the er, the biggest thing at the moment I guess is that er I gave up driving, which I considered myself to be the best situation to do that and erm I'm just carrying on life as normal as possible" (Mr Jones – PLwD)	Resilience means to carry on as normal as possible  Had to give up driving Agency over the decision  Able to maintain life as normal as possible	Maintaining a normal life	Understanding resilience
"I suppose its, well I would interpret it as fighting against it, condition, fighting against what its making him into sort of thing, and making our	Resilience is fighting against the dementia	Fighting the dementia	

lives" (Mrs Roberts –	Fighting against the		
caregiver)	progression of the		
	dementia		
	Fighting against the		
	effect it has had on their		
	lives		
"Ah well for me I just see it			
as I I I'm a great believer in	Remaining optimistic		
looking on the bright side of	and looking on the	Dogitivites and	
things and when it happened,	bright side	Positivity and	
er [PLwD], you were well in	Happened later on in	optimism	
your 80s by then" (Mrs	their lives		
Brown – caregiver)			
"we've had to face up to			
problems in life like that and			
that's the approach. [cough]	Resilience is always		
pardon me, no matter what	the approach they		
you've got, you've got to	have taken in		
you know erm [daughter]'s	previous problems		
gone from being 7 years of	faced		
age, [daughter] was	It is not just about the	Forly ovnorionoss	
diagnosed as being a type 1	dementia, they have	Early experiences	
diabetic and er last year we	had to deal with other		Developing
do we do we do [cough],	health concerns and		resilience
pardon me, this was all	issues too – resilience		
happening to [p1] and then	has been helpful for		
[daughter], our eldest	this too		
daughter erm cancer" (Mr			
Wood – caregiver)			
"my wife died quite a while	Resilience develops	Previous	
ago and then went to	due to adversities you	experiences	
[county] and then I met	have faced	capononees	

[caregiver]" (Mr Williams –	Resilience continued		
PLwD)	to develop after		
	meeting partner		
"That's the other thing I do	The caregiver reads		
you see, I read everything	any information		
don't I? If there's any	available		
information then I'd read it,	If there is a	Learning/ having	
if there's programmes on it	programme on TV	information about	
I'll watch it, because even if	about dementia she	the dementia	
you only learn one thing,	will watch it		
even if only one thing helps	Learning even one		
you, it's beneficial isn't it?"  (Mrs Thompson – caregiver)	thing is beneficial		
(wits Thompson – caregiver)	Family are a good		
"I lean as much as I can on	source of support		
the family, without			
overdoing it I try not to	Shouldn't ask them	Family support, but	
bother at all, asking them for	for too much	not becoming	Maintaining
anything, they just do it" (Mr	This might both them	overly reliant	resilience
Smith – PLwD)	They do everything		
,	that you ask of them		
	Support groups		
"there are erm places in	enable people with		
[city] where lots of people	dementia to meet		
get together who have	together		
dementia erm for me in	Seeing other people	Meeting others	
particular but I think its you	with dementia	with dementia at	
know, you see them and you	normalises the	support groups is	
think oh there's nothing	experiences, and	helpful	
physical about it, it's just up	enables you to realise		
here" (Mrs Edwards –	that it is just your		
PLwD)	brain		

#### **Appendix O: Epistemological Statement**

Within research it is important to consider a researcher's personal perspective and how this may have impacted on the approach taken. This statement, therefore aims to explore the ontological and epistemological assumptions which may have influenced the research. Ontology refers to the nature of existence and the views of the researcher whilst epistemology can be understood as the theory and development of knowledge (Ritchie, Lewis, Nicholls & Ormston, 2013).

The purpose of the research was to explore the lived experience of people living with dementia, researching from a more holistic perspective as opposed to the vast amount of research which chooses to focus on the negative aspects of life with dementia. Focusing on the lived experience of people living with dementia and their caregivers enables researchers to understand a person's subjective experience (Górska Forsyth & Maciver, 2018). In order to develop such an understanding it was felt that a qualitative approach would be most suitable.

Bryman (2012), states that there are 2 positions which can be taken within social research, a positivist or a constructionist stance. Positivism considers an objective reality in which there is an objective truth to uncover and the researcher is independent from the findings. The positivist position, therefore, assumes that the researcher will not influence the findings (Ponterotto, 2005). As this stance was considered to be too reductionist for the complexity of resilience (Wiles, Wild, Kerse & Allen, 2012) and the positivist stance is usually associated with quantitative methodology (Willig, 2001) this stance was felt not to be appropriate.

Constructionism challenges the positivist stance, stating instead that the meanings of phenomena are continually changing as a result of social interaction (Bryman, 2012). This stance considers that there is not an objective truth to be uncovered, rather viewing

truth as a social reality (Guba & Lincoln, 1994). Within this viewpoint, the researcher is considered as a contributor to the findings of the research (Ponterotto, 2005), in that the knowledge of the researcher and their own preconceptions and assumptions affect the way in which they understand and interpret participant's own experiences (Charmaz, 2006). Research from a constructivist stance assumes that the analysis and meaning-making process is a collaborative approach between participants and the researcher.

When taking a constructivist perspective, research reflexivity is important where the researcher considers their own experiences in relation to the research and how this may impact on the analysis of findings (Charmaz, 2006). The researcher had previously volunteered with people who had been diagnosed with dementia, empathising with the adversities associated with diagnosis, especially in those who were in a progressive state of decline as a result of having lived with dementia for longer. The researcher also had experience of family members living with dementia and family members who had experience of caring for people with dementia. The researcher was therefore aware of the complexities and difficulties associated with caring for a family member living with dementia and the progression of this throughout the diagnosis. Finally, the researcher was mindful of the Government National Strategy, "living well with dementia", which aimed to improve services to meet the needs of people with dementia and their caregivers, improving knowledge about dementia and supporting earlier diagnosis (Department of Health, 2009). It is possible that the experiences and knowledge of the researcher could have influenced the way in which the researcher conducted the interviews and analysed the data, and so this was important for the researcher to reflect upon.

Due to the aforementioned complexities of resilience (Wiles et al., 2012), the importance of considering the lived experiences of participants within the research, as well as the importance of researcher reflexivity, a constructionist stance was taken. The present study took a dyadic perspective and aimed to develop an understanding of the

shared resilience in people with dementia and their caregivers, understand how couples were able to develop and maintain their resilience as well as considering the impact this had on their relationship and well-being. The study aimed to build a theory in relation to the shared resilience of couples living with dementia; as Dias et al. (2015) emphasise in their literature review there is a need for a theoretical framework from which further dementia resilience research can be based.

Different research methods were considered; however, Constructivist Grounded Theory was felt to be the most appropriate as opposed to Interpretative Phenomenological Analysis (IPA) to address the research questions of the study. IPA aims to understand the lived experience of participants and the meaning of such experience (Smith & Osborn, 2008). This methodology explores the meaning from an individual perspective and then considers the wider context of the data set as a whole (Smith, Flowers & Larkin, 2009). IPA considers the phenomenology — the individual experience of participants; hermeneutics — the interpretation which is co-created by the researcher and participants; and finally, the idiography — in which there is a focus on the individual and the unique experiences they have within their wider context (Smith et al., 2009). Due to the present study aiming to develop a theory of shared resilience rather than solely exploring the individual experiences of resilience IPA was rejected.

Constructivist Grounded Theory aims to develop a theoretical and reflexive understanding of a phenomenon, whilst considering the social context in which the research occurs (Charmaz, 2006). This is particularly important when carrying out qualitative resilience research (Ungar, 2003). Constructivist Grounded Theory allows for researcher reflexivity, enabling the researcher to think about how their interpretations may have had an impact on the analysis of data (Charmaz, 2006). Analysis of data, as recommended by Charmaz (2006) includes, 'initial coding' in which the data is coded line by line, 'focused coding' in which the most frequent initial codes are then put into

categories and finally, 'theoretical coding' in which the categories created in focused coding are compared in order to see how these are related or similar to one and other, and how these can then be integrated into a theory. Within Constructivist Grounded Theory theoretical sampling can be used to help decide where the next piece of data comes from based on previous data collection. The use of theoretical sampling ultimately aids the development of a theory which is grounded. Constant comparative analysis is another key aspect of Constructivist Grounded Theory in which analysis of data takes place at the same time as data collection so that the researcher is able to identify gaps in the research and developing theory (Glaser & Strauss, 2017). Collection of data continues until data saturation is reached where further collection of data will not lead to any additional information related to the research question, the themes and emergent theory (Holton, 2007).

Constructivist Grounded Theory was therefore considered to be the most appropriate methodology to use due to the research questions as well as the need to develop a theoretical framework for resilience in dementia research. In addition to this the methodology's ability to consider researcher reflexivity was felt important as a result of the complexity of resilience (Wiles et al., 2012) and the researchers' previous experiences of people living with dementia and their caregivers. Finally, the use of Constructivist Grounded Theory also supported the constructionist stance that had been taken by the researcher.

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#### **Appendix P: Reflective Statement**

#### The Research Topic

My initial interest in dementia began when my stepfather, who worked with people living with dementia, would come home and reflect on his day. Prior to this I had little awareness of dementia. However, after hearing him talking about his role with passion and excitement, as well as the people he was supporting with warmth and empathy, I too became interested in in this area and in particular wanted to understand how I could empower and ultimately aid people to live well with dementia. Whilst doing my undergraduate psychology degree I began volunteering with people living with dementia in a baking group. Whilst volunteering I was struck by the positivity within the group despite the adversities associated with their diagnosis. The majority of those attending were able to remain positive, reminisce, and continue living a life which brought happiness and fulfilment. This experience consolidated my interest in dementia, especially considering the ways in which people were able to "live well with dementia" in the face of a common narrative of loss of life once diagnosed.

Upon beginning the Clinical Psychology Doctorate I began meeting with Dr Emma Wolverson and Dr Chris Clarke in order to think about how my interest in dementia, especially living well with dementia, could be structured into a research proposal and later a research project. Together, we considered aspects of positive psychology, a particularly interesting area of research for me due to the lack of research in this area. When discussing with Emma and Chris I was drawn to the notion of resilience, in which people can go through a number of adversities, yet are able to continue living, flourish and maintain a quality of life. Furthermore, it was felt that by considering the couple within the research as opposed to just the caregiver or the person living with dementia, it allowed for an appreciation of the relationship and thereby offering a different but no less important understanding of the experience of living with dementia.

#### Methodology

When originally designing my doctoral research mixed methods felt most appropriate; in which participants would be given resilience measures and those with scores considered to be within the high range of resilience would be invited to an interview to talk about their experiences of living with dementia. However, after some difficulties with recruitment centres, it was felt that recruitment for a mixed methods study would not be feasible. Whilst I was disappointed that the original research proposal was no longer feasible, it became apparent that there are a number of ways in which resilience can be conceptualised within dementia and therefore measured. On reflection, it felt more appropriate to utilise a qualitative methodology in which participants were purposively sampled if they considered themselves to be a resilient couple. This enabled couples to consider their own definition of resilience rather than a predefined one. Utilising this methodology enabled me to consider in more detail the way that couples conceptualised resilience together as well as their lived experience of this concept.

A literature review in the resilience of caregivers of people with dementia emphasised the need for a theoretical framework from which further resilience research can be based, therefore the current research aimed to build a theory of shared resilience. Due to wanting to build a theory the use of Interpretative Phenomenological Analysis was considered unsuitable and Constructivist Grounded Theory was deemed as the most appropriate methodology for my research aims and questions. I felt some trepidation with regards to the development of a theory and reaching data saturation; however, after discussing the analysis in practice with a peer in the year above, I was reassured that this analysis was appropriate and achievable for a doctoral thesis. Being able to discuss the use of Constructivist Grounded Theory with peers was invaluable, in particular reading

recommendations from peers was particularly helpful in order to further my understanding.

#### Recruitment

Due to concerns that the recruitment of couples who considered themselves to be resilient could prove difficult, I considered very carefully where I would recruit from. This was especially important for Constructivist Grounded Theory which values purposive and theoretical sampling in order to address gaps in the emergent theory. I began creating links with local NHS trusts as well as researching the process of advertising my research on the Join Dementia Research database. Furthermore, with the help of Emma and Chris I was given contact details of research and activity co-ordinators, who we hoped would also provide support regarding recruitment.

Upon making contact with a number of professionals to discuss my research I was both relieved and reassured by their interest in my topic and resulting support of recruitment. This provided me with confidence that I would be able to reach data saturation with the help and support of the agreed research sites. I also attended a number of groups in order to become familiar with those attending and so was well received when presenting my research during a break. This resulted in the successful recruitment of participants to the study.

Furthermore, the first couple I recruited were involved in local social activities and research and as a result had a number of friends who were also willing to take part in my research. This was a great relief to be able to secure so many interviews; however, due to a few of the couples being friends, their views of resilience and ways to maintain resilience as a couple appeared quite similar. Therefore, recruiting couples through Join Dementia Research provided some diversity, as it enabled me to consider the views of couples who were often not attending support groups and in most cases were younger

(due to the need to be computer literate to view the research projects which they had matched with online). This enabled me to address gaps in the emergent theory.

#### **Interviews and Analysis**

Before conducting the interviews I asked for some feedback from my grandparents about their understanding of the information sheet and interview schedule. This was very useful as it enabled me to consider the jargon used, as well as consult with them as to how best to reword and explain the research in a way that was meaningful for the couples taking part.

Upon recruiting my first couple I felt incredibly nervous about the interview, feeling worried that I would not do it 'perfectly'. However, once inside the first couples' home I was soon calmed by their openness and warmth and thoroughly enjoyed listening to their stories. Each interview subsequently was equally enjoyable and I often reflected upon what a privilege it was to be invited into each couples' home for them to share their experiences with me. After finishing each interview I would leave feeling optimistic about the positives that could be taken from a dementia diagnosis and the adversities that couples were able to overcome; this resulted in a growing passion for my research.

Due to the Constructivist Grounded Theory methodology, I was required to transcribe and code each interview before conducting the next interview. I was surprised by how long it took to transcribe each interview, resulting in the process becoming tiresome at times. Due to the time taken to transcribe and the limited time to complete the doctorate, there was not much time to code and consider possible changes to the interview schedule in order to theoretically sample. It may therefore have been beneficial to begin interviewing earlier so that there was more time between each interview to transcribe, code and theoretically sample.

#### Write-up

When writing up my research, it felt important to be able to harness the optimism and passion that I had had during the interview stage, whilst also wanting to do justice to the stories and lived experience of the couples interviewed. At points this felt very difficult as the challenge was to do this succinctly, within the word limit of my chosen journal whilst holding onto the essence of each couples' experiences. Both Emma and Chris were invaluable in guiding me through this process.

#### **Systematic Literature Review**

When choosing a topic for a literature review, it felt important to consider resilience within dementia. There had already been some literature reviews which considered the perspectives of caregivers and factors which affected their resilience from a quantitative perspective. It therefore felt as though there was a lack of understanding around the experiences of resilience from a qualitative perspective. Furthermore, with previous research suggesting the importance of dyadic research it felt useful to consider the needs of the other person within the dyad and the impact that their resilience had on each other. Therefore, I made the decision that I would carry out a systematic literature review of resilience in dementia from a dyadic perspective. At times the process felt difficult, especially as resilience was often conceptualised differently, resulting in findings from the studies being organised and reported in different ways. This made the synthesis of data particularly challenging and at times overwhelming.

Despite these difficulties, I was able to consider the scarcity of dyadic research into resilience within dementia, as well as the lack of voices of people with dementia in the research. As a result of these conclusions I became excited about my empirical research and the gap this would fill within the existent literature.

#### **Choice of Journals**

I chose to write for the journal of 'Dementia' for my empirical paper, an international peer reviewed journal which welcomes research relevant to improving the lives of people with dementia and their family. This journal therefore felt like a suitable place to publish my findings, as I hoped one day my findings would be able to help those who are less resilient, developing dyadic interventions in order to increase resilience. For my systematic literature review I chose to write for the journal 'Aging & Mental Health' which aims to understand the relationship between ageing and mental health. The journal publishes literature reviews and therefore it was hoped that my Systematic Literature Review would be able to provide an overview of how people maintain their well-being despite the associated adversities of dementia.

#### **Final Reflections**

Whilst carrying out my research I was struck by the kindness of everyone involved who helped me complete my research: participants, supervisors and professionals, and I wholeheartedly value the support that was provided. I felt so fortunate to be welcomed into the homes of couples in which they shared some of their most treasured memories.

Throughout my research I have learnt a lot about my views and the assumptions that I hold. For me, I felt most comfortable when listening to the positive experiences which couples reflected on, finding it particularly difficult when couples spoke about what their future might look like or what the future might hold for them. This may be due to my own naivety when beginning the research as I assumed that due to researching positive psychology, I would only be listening to a couples positive experiences and memories. On reflection, despite resilience being rooted in positive psychology, a couples' resilience has been found to develop from difficult experiences and adversities, and so

their story of resilience could not be told without talking about some of the difficult experiences that they had had or envisaged they would have in the future.

My experience of the research has not been without difficulties and at times it has felt overwhelming. However, it has been such a rewarding experience and has enabled me to grow, not only as a researcher, but also as a clinician. The skills that I have developed throughout the process will aid me in my career as a clinical psychologist and I hope to continue researching with the aim of improving services and the quality of life of those that I am supporting.