



An Exploration of the Experiences of People Living with Dementia

Louise Sheppard

Doctorate in Clinical Psychology

Supervised by:

Dr Warren Donnellan

Dr Sarah Butchard

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University of Liverpool

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Contents

Introduction: Thesis Overview	7
Chapter One: Systematic Review	9
Abstract	10
Introduction	11
Social Support.....	12
Current Review.....	13
Method	14
Search Strategy	14
Inclusion/Exclusion Criteria	16
Process of Study Selection	17
Quality Assessment.....	17
Data Extraction	20
Data Synthesis	20
Reflexive Statement	21
Results	25
Quality Assessment.....	25
Demographics	26
Theme One: A Shrinking Social World	26
Loss of Relationships	27
An Inevitable Consequence	28
Meaningful Connections.....	28
Theme Two: Impact on Wellbeing	29
“A person can only take so much”	29
A Process of Adaptation.....	30
Theme Three: Sharing as a Way of Caring	30
Expanding Communities	31
Sources of Support	31
Discussion	32
Strengths and Limitations.....	35
Implications for Practice	37
Future Research	38
Conclusions	39
References	40
Chapter Two: Empirical Paper	48

Abstract	49
Introduction	50
Method	55
Ethical statement.....	55
Participants	55
Inclusion and Exclusion Criteria.....	57
Data collection	58
Data analysis.....	59
Results	62
Couple Level.....	65
Hindering factors.....	65
Facilitating factors.....	66
Moderating factor.....	68
Community Level	68
Hindering factors.....	68
Facilitating factors.....	70
Moderating factors	71
Societal Level	72
Hindering factors.....	72
Facilitating factors.....	74
Discussion	75
Strengths and limitations	80
Clinical Implications	83
Suggestions for Future Research	84
Conclusions	85
References	86
Appendices	96
Appendix 1. Author Guidelines for Aging & Mental Health	96
Appendix 2. Email exchange regarding review topic.	101
Appendix 3. Search Strategy.	102
Appendix 4. Inclusion Exclusion Criteria.	103
Appendix 5. CASP Tool.....	104
Appendix 6. Data Extraction Tool.	110
Appendix 7. Process of Code Generation for Thematic Synthesis.	111
Appendix 8. Which Papers Contribute to Themes.....	116
Appendix 9. Sponsorship Approval.....	118
Appendix 10. HRA and NHS Ethical Approval.....	119

Appendix 11. Reflexive statement.....	127
Appendix 12. Study Poster.....	129
Appendix 13. Participant Information Sheet.....	130
Appendix 14. Ecomap Example.....	137
Appendix 15. Interview Schedule.....	138
Appendix 16. Example of Emerging Narrative – Appendix Edited to Ensure Participant Anonymity.....	140
Appendix 17. Full List of Codes.....	144
Appendix 18. Example of Code Condensing.....	150

List of Tables

Table 1. SPIDER tool.....	15
Table 2. Search terms.....	15
Table 3. Articles assessed with the CASP tool.....	19
Table 4. Data extraction from articles included in the systematic review analysis...	22
Table 5. Participant demographics.....	58

List of Figures

Figure 1. PRISMA diagram.....	18
Figure 2. Ecological resilience framework (Windle & Bennett, 2011).....	53
Figure 3. An ecological resilience framework for couples living with YOD.....	64

Word Count

Section	Text (titles, tables & figures included)	References (not included in total)
Introduction	542	
Systematic review	7781	1581
Empirical research	10,021	
Appendices	195	1865
Overall total	18,539	

Introduction: Thesis Overview

This thesis includes two papers, comprised of a systematic review and an empirical research project. Both have been prepared for submission to *Aging & Mental Health* (Appendix 1 for submission guidelines).

Most care provided to support people to live well with dementia is done so via unpaid or informal carers (Lewis et al., 2014). These carers are often family members; children (40%) or romantic partners (26%; NHS Digital, 2010). Research has often focused on perceived feelings of burden that carers experience, however, not all carers experience this or respond to stressful situations in this way (Denckla et al., 2020). This leaves the question: why do carers respond differently? One way to investigate this is through exploring resilience (Windle & Bennett, 2011).

The systematic review sought to synthesise qualitative data exploring the social support of carers who supported a family member living with dementia. Access to, and engagement with, social support is one resource which aids coping with adversity (i.e., promotes resilience; Donnellan et al., 2015). By focusing on qualitative methodology only, the richness of participants' experiences could be studied. Eight papers were deemed eligible for the review. They were appraised for their quality using the CASP tool and data was analysed through thematic synthesis. Three analytical themes were composed to incorporate seven subthemes: a shrinking social world; impact on wellbeing; sharing as a way of caring.

The systematic review findings highlighted there was a reduction in social support for familial carers, negatively impacting on their wellbeing. However, after carers adapted to their changed circumstances, where possible they found avenues to increase their social support in ways which supported their role as a caregiver, for example joining dementia support groups. Carers found value in sharing their

experiences with others in a similar position. Where the carer's wellbeing had been negatively affected and they could not rebuild their social networks, this led to interventions from health care professionals.

The empirical study sought to explore the experiences of cohabiting couples, where one person in the couple was living with young onset dementia, using the ecological resilience framework (Windle & Bennett, 2011). This framework identifies resources missing or available to people within themselves or in their wider environments, such as social support. A dyadic approach was employed as this is underutilised in research, with more of a sole focus on carers. Furthermore, there is less empirical evidence exploring the lives of those living with young onset dementia compared to dementia diagnosed after the age of 65.

The use of Constructivist Grounded Theory enabled the development of the ecological resilience framework by incorporating couplehood, reflecting the resources available to those living with young onset dementia. An additional tool was employed (ecomapping) which allowed for further exploration of the social support and wider systems couples had access to, incorporating triangulation into the analytic process.

An ecological exploration of resilience highlights numerous avenues of intervention or support which could be offered to people living with dementia. These implications are discussed further.

Each chapter of this thesis adds to the evidence base as they explore both the positive and more negative experiences that people living with dementia encounter. By understanding their experiences, health and mental health care professionals can begin to consider their role in this also.

Chapter One: Systematic Review

How Does Social Support for Unpaid Carers Change Following their Family Member's Diagnosis of Dementia?

Louise Sheppard

Department of Clinical Psychology, University of Liverpool, Liverpool, United Kingdom

For correspondence:

Louise Sheppard

Department of Clinical Psychology

Eleanor Rathbone Building

74 Bedford Street

Liverpool

L69 7ZA

Tel: 0151 7945530

Email: l.sheppard2@liverpool.ac.uk

Abstract

Objective: Social support impacts on a person's wellbeing. This study synthesised qualitative data exploring this for unpaid carers following their family member's diagnosis of dementia. If changes in social support occurred, the impact was explored.

Methods: Five electronic databases (PsycINFO, CINAHL, PubMed, Academic Search Complete, and Social Care Online) were searched in October 2021 and March 2022 for peer-reviewed, qualitative studies. Eight articles were included in the review following methodological appraisal of their quality and the results of the studies were combined using thematic synthesis.

Results: Three analytical themes were composed with seven subthemes: A shrinking social world (Loss of Relationships, An Inevitable Consequence, Meaningful Connections); Impact on wellbeing ("A person can only take so much", A Process of Adaptation); Sharing as a way of caring (Expanding Communities, Sources of Support).

Conclusion: Social support for familial carers reduced, negatively impacting on their wellbeing. Time became a valuable commodity for carers, impacting on what they felt they could take part in outside of their caring role. Dementia-related supports (e.g., dementia support groups) could be shared with the person they cared for. These opportunities offered chances to meaningfully connect with other carers. Where carers could not rebuild their social networks, they sought support from health care professionals. Implications of findings are discussed.

Keywords: Dementia; social support; familial carers; unpaid carers; wellbeing

Introduction

In the UK, approximately 700,000 people provide a caring role for a loved one with dementia (Lewis et al., 2014). Over half (63%) were retired, with 36% reporting they spend over 100 hours a week providing this support. In a report published by Alzheimer's Research UK (2015), carers highlighted numerous ways their lives had changed since adopting a caring role for a loved one with dementia. These included poorer physical health outcomes and experiencing symptoms of depression and exhaustion.

One of the biggest changes carers reported was in their relationships, with some reporting feelings of social isolation (Alzheimer's Research UK, 2015). Of those who provide unpaid or informal care to a person living with a dementia, 63.5% reported feeling as if they had little to no social support (Alzheimer's Research UK, 2018). Research has also highlighted this as a problem. Donnellan et al. (2017), for example, interviewed carers who supported their spouses living with dementia. Those who identified having limited access to resources to help their caring experience reported that their friendships fell away after the adoption of their caring role.

Approximately two thirds of familial carers of a person with dementia report feeling lonely. Those who experienced loneliness also noted having a small social network and reduced quality of their existing relationships (Victor et al., 2020). Loneliness has been shown to increase the risk of developing health conditions such as stroke, coronary heart disease and Alzheimer's disease, as well as negatively affecting an individual's wellbeing (Holt-Lunstad & Smith, 2016). Loneliness has been recognised by the UK Government as an area which requires exploration and action to support people to develop meaningful relationships (Department for Digital, Culture, Media and Sport, 2018).

Social Support

Social support has been defined as a resource exchanged between people which enhances the wellbeing of the individual in receipt of it (Shumaker & Brownell, 1984). Furthermore, it refers to an individual's perception of what support they believe is available to them through their social networks. Social networks are the number of social relationships an individual has, and the number of contacts between each person within the network (Kelly et al., 2017). The support an individual receives through their social relationships has been divided into four categories: emotional (amount of care, love and understanding provided by others); instrumental (help with daily living activities such as shopping); appraisal (support with making decisions or providing feedback); and informational (giving advice; Berkman et al., 2000).

Numerous effects on wellbeing have been shown. For those in a caring position, relationships in their social networks which provide a social support role have a beneficial effect on perceived stress, by contributing resources which aid with the management of difficult situations (Windle & Bennett, 2011; Sapolsky, 2004). The quality and quantity of social relationships has also been correlated with positive affect, subjective wellbeing, mental health, and improved physical health outcomes across the lifespan (Diener & Seligman, 2002; Holt-Lunstad et al., 2010).

A diminishing number of social contacts have been evidenced for informal dementia carers (Clay et al., 2008). Carers report the act of supporting a person with dementia negatively affects their social lives due to the requirements of providing this support, with limited time and finances to take part in any recreational activities (Vlachantoni et al., 2020). Lindeza et al (2020) conducted a systematic review exploring the views of family carers on different aspects of providing care. One theme centred on the carer's social lives, highlighting how friendships prior to the dementia diagnosis had

diminished over time, leaving the carer to turn to more formal options, such as health care, to support them.

Although spouses report feeling abandoned by their social supports once they begin to care for their partner, leading to feelings of isolation, some go on to form new supports by seeking out those who are in a similar position to themselves (Denham et al., 2019). Studies highlight that when carers believe they have social support via friendships or family, and engage with this, they feel more confident in providing care (Kelley et al., 2017) and their own physical health shows improvement (Chan et al., 2021). Therefore, both loss of and the introduction of new social relationships are reported by those in caring roles.

Current Review

This systematic review seeks to synthesise qualitative literature exploring the impact of changes in social support for a familial carer of a person living with dementia. Research has focused on the relationship between the informal carer and the person living with dementia after their diagnosis, but less so on the social relationships and perceived social support outside of this dyad. Roth et al. (2005) have shown that the quality of social support along with its availability predicts a carer's wellbeing more so than the size of their social networks. Therefore, social support is important to carers of a person with dementia. It is of benefit to understand how this social support changes for a familial carer following their loved one's dementia diagnosis. Therefore, this will be the focus of this synthesis which will employ a thematic synthesis approach (Thomas & Harden, 2008) to answer the following questions:

- (1) What happens to the social support of an unpaid carer following their family member's diagnosis of dementia?

(2) If a carer does experience changes to their social support, what impact does this have for them?

Method

This systematic review was registered via the PROSPERO database (ID number: CRD42021256393). Prior to submission, this database and Google Scholar were searched to identify any similar existing, or planned, systematic reviews. Researchers in this field were also contacted via email to ensure the systematic review was not a duplication (Appendix 2). PRISMA guidelines for the reporting of systematic reviews were followed (Page et al., 2021).

Search Strategy

The review question was broken down into constituent parts using the SPIDER tool (see Table 1; Cooke, Smith & Booth, 2012). Search terms were generated and then reviewed by the supervisory team. In addition, an NHS Trust librarian was consulted who helped to structure the search terms (Table 2) and review the chosen databases. They suggested the addition of Social Care Online, which was subsequently added to the databases being searched. The search strategy can be found in Appendix 3. Each line of the search was conducted separately (for example, dementia specific terms, followed by carer specific terms and so on) and then combined to return a final number of articles for review.

Table 1. SPIDER tool.

Element	Term	Criteria
S	Sample	Carer of a family member living with dementia
PI	Phenomenon of Interest	Social support received by dementia carers
D	Design	Interviews, focus groups, written forms of communication (e.g. blogs/social media)
E	Evaluation	Change in social support following the adoption of a caring role
R	Research type	Qualitative

Table 2. Search terms.

	Search Terms
Carer of a family member living with a dementia	unpaid OR informal AND care* OR caregiv*
Dementia caregiving	dementia OR alzheimer*
Interview or focus group	interview* OR “focus group*”
Change in social support following the adoption of a caring role	“social support” OR famil* OR friend* OR relations* OR interpersonal
Qualitative	qualitative

In October 2021, literature searches were conducted via the following databases: PsycINFO, CINAHL, PubMed, Academic Search Complete, and Social Care Online. Healthcare Databases Advanced Search (HDAS) was used to search PsychINFO, CINAHL, and PubMed. Searches were updated in March 2022 to check for additional publications. A total of 112 results were found during this later search. No new papers were identified that met the inclusion criteria for the review. A final search was

conducted directly via PubMed in July 2022 which was also checked by a university librarian. This returned an additional 15 articles. None of the 15 additional papers identified met the inclusion criteria and therefore did not impact on the results presented below.

Inclusion/Exclusion Criteria

For inclusion in the review, papers were required to meet the following criteria (Appendix 4): papers which focused solely on familial adult carers as participants; who cared for a person living with any type of dementia; the terms “social” and/or “support” contained within the aims or objectives of the research with a focus on relationships outside of the family; qualitative; and accessible in the English Language.

Articles were excluded if participants were not the familial carer, dementia was not the focus, there was no reference to social support outside of the family or there was a sole focus on the relationships between family members. Quantitative studies (including randomised controlled trials) or mixed methods studies were also excluded, as well as studies which were a type of intervention, as these did not solely focus on the qualitative experience of the carer. In addition, articles were excluded if they were books, conference presentations or an unpublished dissertation as these had not been subjected to a peer review. Articles exploring or evaluating the impact of Covid-19 on carers were also excluded for several reasons: a pandemic is an additional and unique stressor, and research into this area is ongoing and may benefit from its own systematic review in future. Additionally, Covid-19 had a major impact on the levels of social support a carer received.

Process of Study Selection

In total, 1,427 articles were returned in the search (PsychINFO = 250, Pubmed = 395, CINAHL = 293, Academic Search Complete = 341, Social Care Online = 148), including those papers found during the search update in March 2022 and July 2022. When screening, 662 duplicates were removed. Through applying the inclusion and exclusion criteria, an additional 728 papers were removed at the abstract stage. The full text of 37 articles were reviewed, where the final number of eight articles was reached for thematic synthesis (Figure 1). A second rater applied the same criteria to 27 of the eligible papers (n = 6) for interrater reliability (McHugh, 2012) in March 2022. A librarian supervised this process in July 2022. Cohen's kappa came to 83.33% indicating almost perfect agreement. After discussion of the disagreement, agreement came to 100% (Cohen's kappa = 1.00).

Quality Assessment

To critically assess the quality of papers included in the synthesis, the CASP assessment tool was utilised (Appendix 5; Critical Appraisal Skills Programme, 2018). The CASP tool is a frequently employed tool to appraise the quality of qualitative evidence (Long et al., 2020). A second rater also independently applied the CASP tool to all 8 final articles. There were some discrepancies in scoring, often in relation to the researcher's relationship to the participants and the data. All discrepancies were discussed between the raters and an agreement was reached. Table 3 includes information from the CASP evaluation. This table shows that the article by Anderson et al. (2018) was assessed as answering 'yes' to most areas of the CASP tool, indicating a higher quality article compared to others which were assessed. The majority of studies did not discuss ethical issues, or make reference to processes of rigour in the analysis and generation of themes.

Figure 1. PRISMA diagram.

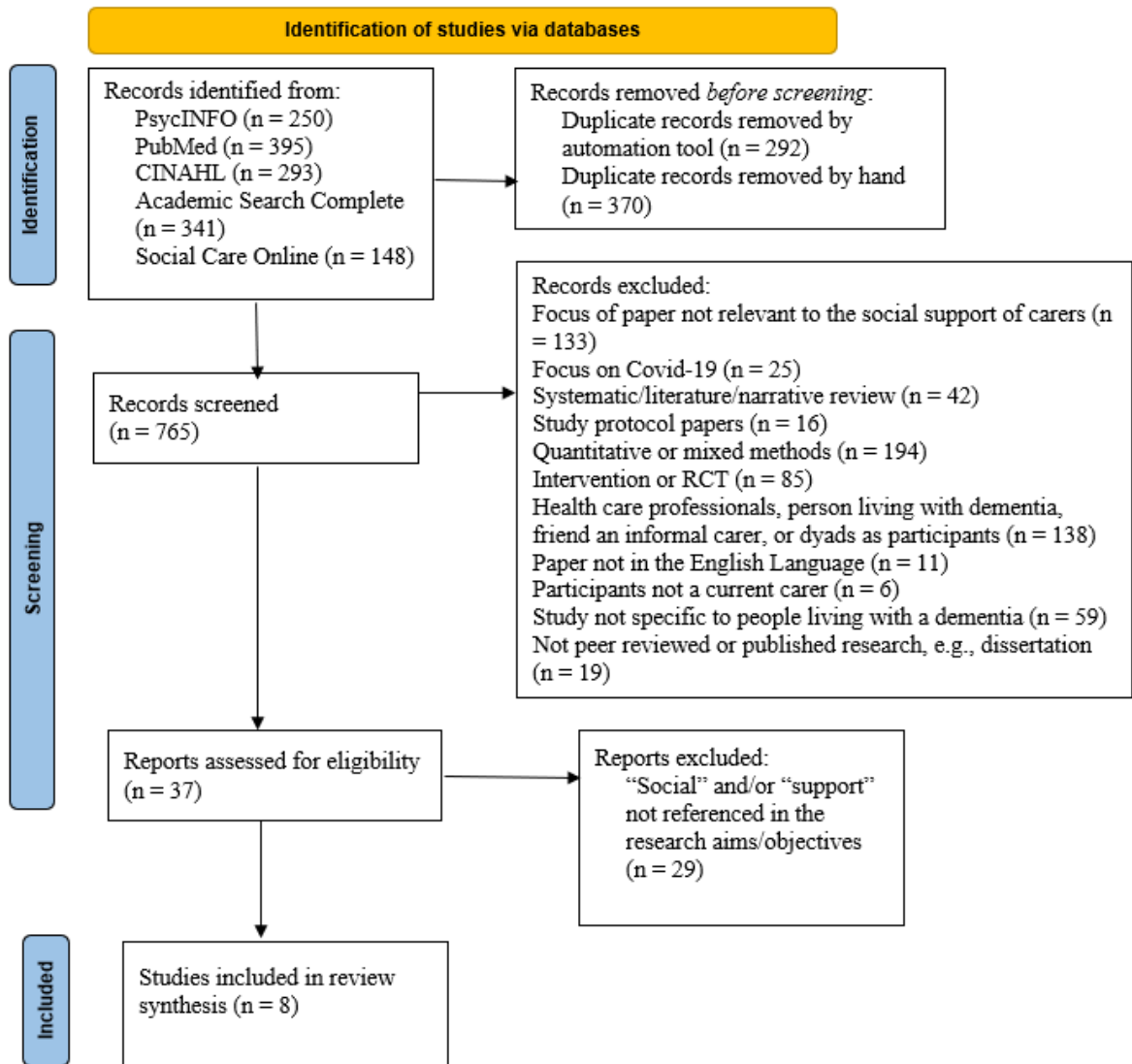


Table 3. Articles assessed with the CASP (2018).

Author	Aims	Methodology	Design	Recruitment	Data Collection	Researcher Relationship	Ethics	Rigour	Findings	Valuable
West et al. (2019)	Yes	Yes	Yes	Can't tell	Yes	No	Can't tell	No	Can't tell	Yes
Parkinson et al. (2020)	Yes	Yes	Yes	Yes	Can't tell	No	Can't tell	Can't tell	Can't tell	Yes
Gibson et al. (2019)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes
Orpin et al. (2012)	No	Yes	Can't tell	Yes	Can't tell	No	Can't tell	Can't tell	Yes	Yes
Nay et al. (2015)	Yes	Yes	Can't tell	Can't tell	Yes	No	Can't tell	Can't tell	Yes	Yes
Carpentier et al. (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Mackenzie (2006)	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Yes
Anderson et al. (2017)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes

Data Extraction

A tool was created (Appendix 6) to extract relevant information from studies included in the final analysis. Key information from the studies, i.e., what data was extracted, can be found in Table 4. All papers except for Anderson et al. (2017) employed purposive sampling.

Data Synthesis

The review employed a thematic synthesis approach to the findings of each paper. Thomas and Harden (2008) refined this approach for qualitative systematic reviews by taking methods from Grounded Theory to aid creation of initial codes, leading to analytical themes, to develop additional understandings from the data.

Employing this approach, all information detailed under a ‘results’ or a ‘findings’ section in each article were treated as data to be analysed, including quotations from participants as well as any interpretations made by the original authors.

Articles were added to NVivo 12 to aid analysis. Following guidance from Thomas and Harden (2008), the initial step was a line-by-line analysis of ‘results’ or ‘findings’ sections, applying codes to results or author interpretations relevant to the social support experienced by the familial carer. A comparison between the different studies then occurred. Following this, a hierarchical structure was formed from the codes to aid construction of descriptive themes. Initial codes and themes were discussed within the research team. Analytical themes were then developed from this discussion (see Appendix 7 for process of code generation).

Reflexive Statement

The researcher's prior experience of working in dementia-related services will have had an influential role in the development of the inclusion criteria for article selection. By working with familial carers, the researcher noticed how services can often focus on the individual with the diagnosis and less so their immediate support networks. Therefore, the systematic review was solely interested in the views of carers, limiting the number of papers analysed as participants in numerous studies were also the person with the dementia diagnosis. These excluded studies may have yielded interesting analysis from the perspective of a dyad on how their social worlds had altered following a diagnosis.

During the process of creating initial codes and generating analytic themes, the researcher's position as a trainee clinical psychologist may have meant that the impact on a carer's wellbeing was more attended to than other areas of the participant's experiences.

Table 4. Data extraction from articles included in the systematic review analysis.

Author(s)/Year/ Title	Aims	Participant Characteristics	Location & Setting	Methodology & Analysis	Summary of Outcomes Referencing Social Support
West and Hogan (2019).	To ascertain the perspective of carers who attend dementia support groups.	N = 14 familial carers (11 spouses, 1 sibling, 2 children); 12 female, 2 male Mean age = 70 Ethnicity: White British = 13; White French = 1 Attended support group on average once a week for 2 years	West Midlands, England Dementia support group	Face-to-face semi-structured interviews; Thematic analysis	Familial carers valued sharing their experiences and learning from other carers. Social support from the group meant carers felt less isolated in their experiences. Time is needed after a dementia diagnosis to allow family to adjust before considering attending a support group.
Parkinson, Carr and Abley (2020).	To highlight how familial carers can be supported in the long-term.	N = 18 familial carers (11 spouses, 4 daughters, 3 sons) Mean age = 66.28 years 14 female 4 male Mean number of years in caring role = 4.06	North East England Voluntary sector organisations	Face-to-face semi-structured interviews; Realist evaluation	Seeking social support valuable for emotional and practical support, to mediate stress and prolong care within the family.

Gibson, Holmes, Fields and Richardson (2019).	To explore the familial and community supports of rural caregivers.	N = 11 familial carers Female = 81.8% Male = 18.2% Age of carer = 45.5% under 65, 36.4% aged 66-75, 18.2% aged 76-85.	Midwest America – Ohio and Kentucky Rural communities	Semi-structured interviews (5 face-to-face, 6 via telephone); Thematic analysis	Communities a “safety net” of support for familial carers offering strength and respite. E.g., religious activities offer additional social support which buffered risk of social isolation. Carers reported changes in leisure time, which influenced perceived stress levels as well as life satisfaction.
Orpin, Stirling, Hetherington and Robinson (2014).	To investigate the formal and informal support and how this is used by rural carers of a person with dementia.	N = 18 familial carers (8 of which were the child of the person with dementia; 10 were spouses or partners) Average age = 59 for children; 71 for spouse/partner Female = 8 Male = 10	Tasmania (Australia) Interviews occurred in participants’ homes	Face-to-face semi-structured interviews; Thematic analysis	Carers became absorbed into their caregiving roles. Carers developed strong boundaries to those outside of the caring dyad. Communities experienced as supportive until changes in the person with dementia were more behaviourally apparent.
Nay, Bauer, Fetherstonhaugh, Moyle, Tarzia and McAuliffe (2015).	To elucidate familial carers of a person with dementia’s social participation.	N = 33 (17 were a spouse, 16 were the child/child-in-law of the person with dementia) Female = 27 Male = 6 Age range = 50-59 (40%), 60-69 (30%),	Australia	Semi-structured; Grounded theory	Carers adapted to how they engaged socially following adoption of their caring role, e.g. activities need to have purpose an potential for meaningful connections to be made. Majority reported loss of social participation since becoming a carer. Spontaneity diminished as care needs increased.

		70-79 (17%), 80+ (13%)			Carers feel constrained by caring, feel unable to leave the person with dementia for long, so they do not leave the house.
Carpentier, Ducharme, Kergoat and Bergman (2008).	To investigate barriers to social participation for carers.	N = 52 (adult children = 20, spouses = 32) Female = 78.8% Male = 21.2% Mean age = 66 years	Montreal, Canada Cognition clinics	Semi-structured; Structural Approach to Social Representations (SASR) based on Content Analysis	Friends have an influential role in supporting carers, e.g., accessing services to support the person with dementia or the formation of the carer's illness beliefs. Those friends who could be relied upon when needed were those who had a longstanding relationship with the carer.
Mackenzie (2006).	To explore what the support need is for carers from Eastern European and South Asian communities.	N = 21 familial carers Ethnicity = 11 Pakistani, 5 Indian, 4 Polish, 1 Ukrainian	North East, England	Semi-structured; Content analysis	When someone was diagnosed with dementia, carers aimed to keep this "in the family". Letting other people know what was going on for them invited judgment, impacting on relationships outside of the family. Attending dementia day centres viewed as a way of keeping up appearances of having a social life.
Anderson, Hundt, Dean, Keim-Malpass and Lopez (2017).	To investigate the use of social media (e.g., blogs) for those who care for a person with dementia.	N = 10 blogs of familial carers	Internet – blogs from Westernised countries	Blog content (already written and published via the internet); Content and thematic analysis	Blogs (e.g., Facebook) helped to build an online community for social support, as well as inform prior social contacts of the status of their loved one with dementia. Blogs enabled opportunities to gather information about dementia from other carers. Blogs encouraged carers to connect with other carers in their local areas and beyond, building their social support networks and reducing feelings of loneliness.

Results

The review sought to explore the following questions:

- (1) What happens to the social support of an unpaid carer following their family member's diagnosis of dementia?
- (2) If a carer does experience changes to their social support, what impact does this have for them?

Themes were continually reviewed and refined throughout the analytical process and discussed within the research team. Three overarching themes were generated. Theme one: A Shrinking Social World (comprised of subthemes: loss of relationships, an inevitable consequence, meaningful connections) explored the effects of becoming a carer on social support. Theme Two: Impact on Wellbeing (“a person can only take so much” and a process of adaptation) and Theme Three: Sharing as a way of Caring (expanding communities, sources of support) sought to answer what impact changing relationships has on the carer.

See Appendix 8 for further detail of which papers contributed to each theme.

Quality Assessment

None of the eight identified studies were excluded from the review based on their quality as assessed by the CASP tool. However, all but one of the papers (Anderson et al., 2017) did not report adequate information regarding any ethical issues that arose, such as how the research was explained to participants. The rigour of papers was also difficult to ascertain, often as there was little to no explanation of how researchers derived themes from their data, or any reference to contradictory data. A key piece of information was missing from all but one of the papers (Carpentier et al., 2008); to explain the researcher’s role and any possible biases in the analysis of data, or in the decision of what parts of the data to report on. Additionally, three of the papers (Parkinson et al., 2020; Orpin et al., 2012;

Mackenzie, 2006) did not explain sufficiently how they collected their data. Two of these three papers (Parkinson et al., 2020; Mackenzie, 2006) did not adequately explore their findings with respect to credibility, such as efforts at triangulation.

Overall, five of the eight papers were assessed as being lower in quality. These included Orpin et al. (2012), West et al. (2019), Parkinson et al. (2020), Nay et al. (2015), and Mackenzie (2006). These papers contributed towards all themes presented in this review, particularly for themes one and two A Shrinking Social World and Impact on Wellbeing. As such their findings should be interpreted with caution. Those of higher quality (Gibson et al., 2019; Carpentier et al., 2008; Anderson et al., 2017) provided a theme (theme three) and subtheme (theme one; meaningful connections) which answered both research questions, particularly when considering the impact of social changes on the familial carer. Therefore, themes one and two should be interpreted with caution.

Demographics

The articles included in the review originate from diverse settings, such as numerous different countries (Canada, Australia, America, United Kingdom), some of which have vast rural areas, making certain resources difficult to access (e.g., support groups). Most participants were female caring for a male partner or parent, representing those who take part in research. One study specifically focused on exploring the views of those from ethnic backgrounds other than White British.

Theme One: A Shrinking Social World

This analytical theme encompassed the experiences of the majority of familial carers, namely that they reported a decline in social relationships (i.e., their social network) following the adoption of their caregiving role which led to a decrease in perceived social support.

Numerous studies included within this theme had quality issues relating to transparency, either in the selection of research participants or in the analysis of data, reducing the trustworthiness of conclusions made. Where commentary existed regarding where participants were recruited from, this was often via dementia-related organisations, for example Alzheimer's Australia (Nay et al., 2015). To be aware of these dementia-specific services in the first instance, participants will have needed to have been signposted, conducted their own research, or have members within their social networks who could provide this information. In utilising these specific services for participant recruitment, researchers may have accessed those who were already motivated to build up their social networks, potentially skewing the representativeness of the experiences of familiar caregivers. Additionally, therefore, the experiences of those not accessing these services cannot be reported on under this theme.

Loss of Relationships

Carers reflected on their lives before they began providing a caring role. They recognised there had been various losses, not solely with friendships but also the shared leisure and occupational activities they would take part in with the person now living with dementia (Orpin et al., 2014). These relational losses accumulated throughout the development of the dementia: "I do find myself perhaps cutting myself off a little bit from friends and other people and becoming less sociable", particularly when the symptoms of dementia had progressed to a point where additional support from others was most longed for (Parkinson et al., 2020). The narrowing of social relationships meant that the carer was effectively isolated from others ("Some people well... rarely they come now"), apart from the family member they cared for who could no longer provide the same levels of social support they were once able to.

An Inevitable Consequence

Carers expected to lose social contacts following their loved one's diagnosis ("You're chucked in at the deep end when they are first diagnosed") due in part to the stigma attached to dementia (Mackenzie, 2006). Participants held the perception that their friends avoided the person with dementia, and therefore the carer also, due to discomfort, embarrassment, or fear of the changes in the person living with dementia (Nay et al., 2015). Some carers also avoided people in their social networks, also due to embarrassment of dementia-related behaviours. For participants from cultural backgrounds not often captured in research (e.g., South Asian, or Eastern European), the stigma of a dementia diagnosis was keenly experienced by carers, some of which did not have a word for dementia in their first language. They expressed feelings of shame as they felt blamed by those outside of their family for the dementia diagnosis, e.g., by not praying enough to keep negative life events from occurring (Mackenzie, 2006).

Meaningful Connections

Due to the increased demands placed upon the carer, their time was deemed a valuable resource in which they only had a limited amount to share outside of the caring dyad (Nay et al., 2015; Carpentier et al., 2008). They therefore had to weigh up, and decide, how best to spend their time, including who to spend it with. The carer's role shifted from the singular interests they pursued prior to becoming a caregiver to incorporate their new occupation, adding their loved one with dementia into their social worlds by becoming part of a joint venture, such as dementia support groups ("but when you're at the Memory Lane Café, everybody's in the same boat so people can sort of bounce off one another..."; West & Hogan, 2019). This change coincided with a shift in the carer's values to incorporate aspects of their developing identity (Anderson et al., 2017). By including their loved one with dementia in their social activities, both members of the dyad could create new meaningful

connections, effectively rebuilding or developing their social networks to include those who could provide social support in a purposeful way.

Theme Two: Impact on Wellbeing

The loss of social support carers received due to the diminishing relationships within their social networks negatively impacted upon their wellbeing. However, through expanding their social worlds by incorporating aspects of their new identity, e.g., attending dementia support groups, carers recognised a positive impact on their wellbeing.

This theme was constructed via papers deemed lower in quality when appraised for ethical considerations and aspects of rigour. For example, researchers failed to report on their role in the formation of interview schedules or subsequent data analysis, including how their experiences may have introduced bias into interpretations, i.e., reflexivity. This may have affected the validity of the findings.

Regarding issues of ethics, whilst papers reported having ethical approval for their studies, there was limited commentary on how participants were supported during the data collection process and afterwards. For example, West and Hogan (2019) interviewed participants within their dementia support group environment. It is unclear how much time participants had to consider their involvement in the study, or how any distress may have been alleviated by researchers.

“A person can only take so much”

Participants reported the caring experience as tiring and stressful (Parkinson et al., 2020), leaving them with little time for themselves, or to socially participate with others outside of the caring dyad. With their resources depleted, carers would seek support from professional services, either in the form of medication or counselling (“I’m on antidepressants to be honest... but yeah, it’s a mental strain because you love them dearly and

all that, but... but... a person can only take so much”); Nay et al., 2015). Participants lamented the loss of social aspects of their lives that they had prior to becoming a carer. They recognised they had become fully immersed in their caring role (Orpin et al., 2014). Some participants attempted to keep their decline in wellbeing to themselves, to protect themselves as well as the relationships with those around them (Mackenzie, 2006).

A Process of Adaptation

Participants sought ways of increasing their social activity, such as becoming members of dementia support groups. Initially this was difficult for people to do (West & Hogan, 2019), but once carers adapted to their role and had access to these resources, they noticed a positive effect on their wellbeing, increasing their likelihood of returning (“I think we’d find [not attending] quite erm quite stressful really very lonely in lots of ways.”). Becoming involved in a group related to their caring role continued to link the carer with the person living with dementia, therefore not detracting from their limited resources, but allowed them to nurture their own identity within it. Familial carers could enjoy social interactions without also experiencing guilt, as well as build their skills and knowledge in the area of dementia (West & Hogan, 2019).

Theme Three: Sharing as a Way of Caring

The theme explored participant’s views of their current social lives. The subthemes which comprise this theme were developed from papers deemed higher in quality, with additions from those lower in quality. As such, findings synthesised here could be considered more reliable and trustworthy in comparison to previous themes. Where theme one considered a loss of social support, theme three indicated that carers found value in meeting others also in the position of caring for a loved one living with dementia.

Expanding Communities

As the familial carer's social networks narrowed following their loved one's diagnosis of dementia, carers sought to find and meet with those who could understand and validate their experiences, learn important information from, and not feel judged (West & Hogan, 2019; Carpentier et al., 2008; Mackenzie, 2006; Anderson et al., 2017). Dementia support groups were one such place to "share your caregiving story. Connect with others who understand". Participants reported needing time to come to terms with the dementia diagnosis before they could attend these groups. However, these were environments which could also be shared with the person living with dementia. Therefore, the carer's valuable resource of time outside of the dyad (theme one) did not diminish. Support groups were perceived as a way of making new friendships, rebuilding the carer's social network (West & Hogan, 2019).

Sources of Support

There were those who could not attend or did not have access to dementia support groups, e.g., rural carers. They relied on the longstanding friendships they had created prior to the dementia diagnosis (Carpentier et al., 2008). However, these friends were carefully selected and few in number ("we... eat with them and... he says the same thing all the time but still you know... People just love to talk to him ... they're really, really good with him."). For example, carers sought out the expertise of those in their social networks who had prior experience of accessing healthcare, or who had connections with others who did (Carpentier et al., 2008). If the carer did not have access to longstanding friendships, neighbours were included in their assessment of social support as individuals who might "look out" for them (Gibson et al., 2019; Orpin et al., 2014).

Carers also found creative ways to supplement the social support in their lives by using technology, specifically creating blogs via social media (Anderson et al., 2017). These were viewed as a helpful tool in updating their social networks, but also in creating a

community of people around the carer and person living with dementia, one which was contactable at any time for support or guidance:

Caregivers are a uniquely and intricately woven group of people. Like a cord, alone can be torn in two but braided and banded together, strong yet flexible enough to keep each other supported during the times of caregiving hardships and, celebrate with during times of caregiving triumphs and moments of joy.

Social media use was particularly important for those who wanted to connect with others but saw themselves as more introverted (Anderson et al., 2017).

Discussion

This review focused on the changes to social support, and implications of this, for familial carers of a person with dementia. A total of 1,427 articles were screened, of which eight were selected as they included relevant qualitative information to the review questions. Three themes (comprised of seven subthemes) were developed through a thematic synthesis approach: (1) A shrinking social world; (2) Impacts on wellbeing; and (3) Sharing as a way of caring.

The themes explored how social relationships can diminish for a familial carer following the adoption of their caring role, impacting on the amount of social support they feel they receive. Through the adoption of their caring identity, a carer's social networks built up once again, allowing them access to new relationships who offered social support. When opportunities for giving or receiving social support were minimal, carers recognised the negative impact of this on their wellbeing, leading to seeking support from health care organisations. When carers were able to expand their social networks, and therefore their opportunities for social support, they found sharing their stories to be cathartic, particularly when it offered another carer the opportunity to learn from their experiences.

The findings from this review are generally consistent with evidence previously reported. Donnellan et al. (2017) commented on how carers of a person with dementia noticed a decline in the number of social relationships they had outside of their family. This appeared more likely for those deemed as “non-resilient”, i.e., individuals less engaged in activities they previously were, or struggling to adapt to their current circumstances (Donnellan et al., 2015).

Loss of relationships has been reported elsewhere, leading to feelings of isolation and loneliness for carers (e.g. Greenwood et al., 2019). Carers wish to connect with others who can understand their situation (Shanley et al., 2011). This was evident in the current review (theme one), with carers seeking dementia support groups as one viable option. Donnellan et al. (2017) indicated that joining support groups helped to develop new social relationships. If categorised as non-resilient, carers used support groups for positive social interactions. Those deemed resilient more often used these groups to gain information. Milne et al. (2014) reviewed a group intervention for carers which offered numerous forms of support, including psychoeducation. Carers derived benefit from creating new social relationships which developed feelings of confidence, positively impacting on their ability to provide a caring role.

The current review did not specifically distinguish between types of social support carers received from support groups. However, theme one indicated that carers sought others who could be empathic towards their circumstances, as well as provide opportunities to acquire knowledge. These correspond to Berkman et al.’s (2000) social support categories of emotional, appraisal, and informational support, three key areas for generating feelings of social support (Kelly et al., 2017). The fourth, instrumental support, was not referred to.

Feeling isolated from others, along with stress related to providing care, have both been linked with experiencing loneliness, leading to lower perceived wellbeing (Victor et al., 2020). The current review highlighted a negative impact on wellbeing for carers who had fewer social network members, and therefore limited access to receiving social support. Where this occurred, carers sought help from health care professionals in the form of medications or counselling. This contrasts with research by Walters et al. (2001) who found that carers were reluctant to seek help from services. However, this study was limited to one geographical location so may instead be a commentary on their local resources.

The results of the review indicated that carers adopted a caregiving identity after a period of adjustment to their newly developed circumstances. This has been recognised elsewhere. Tolhurst et al. (2018) highlighted how the nature of providing care to a family member with dementia could present challenges such as minimising opportunities for the carer to have a role outside of their caring responsibility, therefore limiting their ability to express an individual identity outside of the caring dyad. Family members became defined by others as a carer, limiting opportunities to express other elements of their identities, e.g., friend. Tolhurst et al. (2018) argued that in supporting the social wellbeing of the person living with dementia, carers found their own reduced.

The social construction of identity has been discussed by Sabat et al. (2011) in relation to people diagnosed with dementia. In viewing and describing a person through their dementia diagnosis, elements of self outside of the diagnosis are minimised by others, and dementia starts to become the person's whole identity. When the identity of the person living with dementia is altered, this impacts on the identity of the person who provides them with care and support, suggesting therefore that identity construction is dynamic and subject to change depending on responses from social network members (Hayes et al., 2009). There is some support for this in the current review; the family member's identity changed to

incorporate a caregiver persona as they increased the support they provided to their loved one with dementia. Over time, they became immersed in providing this care (Orpin et al., 2014), minimising opportunities outside of the dyad to explore or nurture other aspects of their identities.

Strengths and Limitations

Themes were generated via studies incorporating various geographical locations, including a focus on more rural areas. One specifically gathered data from ethnicities which could be considered underrepresented in research (Mackenzie, 2006). This study aids consideration of why dementia support groups may be less attended by individuals from various ethnic backgrounds other than White British (West & Hogan, 2019) due to stigmatising beliefs and associated feelings of shame. As non-English language articles were excluded from the review, further considerations from different cultures cannot be commented upon. The review also included data collected via more novel means, i.e., dementia caregivers' blogs on social media (Anderson et al., 2017) which helped to explore the experience of social support for those with limited access to in-person support groups.

Following the method of thematic synthesis (Thomas & Harden, 2008), participant quotations were included in the analysis and subsequent reporting of results. Authors may have selected these quotations above others to construct a persuasive narrative, therefore minimising the possibility or representation of contradictions or differing themes (Parkin & Kimergård, 2022). However, as quotations are extracted from data, they help to support the credibility of arguments made by researchers (Eldh et al., 2020) as they represent evidence for interpretations made (Lingard, 2019). By including quotations alongside author interpretations in the synthesis, themes are likely to be more comparable to the experiences of participants recruited in research (Butler et al., 2016).

Of those recruited to the reviewed studies, most carers were female. Whilst this is representative of those who take part in research, there is therefore less consideration of the views and needs of male carers (McDonnell & Ryan, 2013).

The quality of articles was variable, with over half assessed as lower in quality for reasons such as insufficient reporting on process for data collection, or how authors derived themes from their data. As a number of the included studies did not overtly discuss ethical considerations or issues of rigour during analysis and theme generation, less confidence could be placed in the results of this review. Sample sizes also tended to be small, however this is not uncommon for qualitative research (Nay et al., 2015). Only published peer-reviewed research was included in the review, excluding unpublished studies such as dissertations. This decision was made for reasons relating to quality; however this limited the number of studies eligible for the review. Additionally, qualitative findings from mixed method studies were also excluded from the review which may have provided additional evidence to consider.

Studies included in the review were researched and published in Westernised countries, therefore there is no consideration of the lives of those in non-Westernised nations. The search strategy implemented did highlight papers from different cultures, e.g., Japan, however an English translation could not be found, therefore excluding them from the review. Consideration of Westernised bias was also not a feature of the CASP quality assessment tool implemented. Therefore, it is inevitable that this review is biased towards Westernised cultures. However, one paper in the review specifically focused on the experiences of people from Eastern European and South Asian cultures (Mackenzie, 2006). As their findings have been integrated during the process of the review, their more specific cultural considerations could be lost. Caring can be different in different cultures, therefore, further work in this area is warranted.

Implications for Practice

This review highlights several implications for carers, services that support people with dementia, and for wider policy. Carers undergo a transition period where they adapt to their new care-providing roles. During this time, they may lose access to social support. Social support is necessary for the wellbeing of carers, which also impacts on the care they feel able to provide to their family member (Alzheimer's Society, 2019).

Carers should be made aware of ways of creating or finding support following a loved one's diagnosis of dementia. However, the review highlighted it may be more beneficial for carers to access support options such as dementia support groups following a period in which they have adapted to their role as a carer. Dementia support groups act as an intervention to bolster the wellbeing of its attendees (Milne et al., 2014). They also aid the acquisition of knowledge from others about caring and dementia (referred to as informational social support). Therefore, dementia support groups have an important role in supporting the ongoing wellbeing and skill development of those who attend, but at a time when carers have adapted to their caregiving role.

For services, in the current review, when carers had limited access to social support, they sought medical or counselling interventions. However, not all carers may alert health care professionals to the fact that they are struggling to feel supported. Approximately 61% of carers reported a decline in their health following the adoption of a caring role (British Psychological Society, 2018). Carers should be offered assessments as part of the care provided to their family member with dementia, an assessment which explores the biopsychosocial elements of providing care, as outlined in the Care Act (Department of Health, 2014). An assessment of this nature may help to pick up on areas of difficulty and generate discussion around the availability and suitability of support options. However, some resist perceiving themselves as a carer, remaining 'hidden' to services (Knowles et al., 2016).

The care they provide can be construed as a natural element of being a family member (Smyth et al., 2011). Rather than imposing the label of carer, attention should be paid to the language family members use to describe their supporting role. Services have a role to play in identifying those who fall under the carer category but do not label themselves as such to ensure they have access to the appropriate support measures.

Future Research

There are numerous avenues for future research, highlighted by this review. Existing literature (e.g. Donnellan et al., 2017) has indicated that the resources a carer has access to impacts on the type of social support they receive from a dementia support group setting. The current review did not highlight these additional resources. Future research could investigate this further.

The current review accounts for older people living with dementia. Therefore, there was no consideration of the impact of caring for someone with young-onset dementia which can bring additional difficulties (e.g., caring for children, employment; Grunberg et al., 2021) further reducing the amount of valuable time carers have on tasks outside of the caring dyad. This review purposefully excluded dyadic methodology which future research may wish to consider. In doing so, co-constructed meanings can be explored, further developing the evidence base.

The current review also excluded Covid-19 specific studies from the synthesis as this was considered a unique additional stressor to familial carers of a person living with dementia. However, studies such as this would make an interesting contribution as reduced social contact was enforced through government legislation.

Conclusions

A reduction in social support is perceived as inevitable for familial carers of a person with dementia, negatively affecting their wellbeing. Carers undergo a process of adapting to their caring role following diagnosis, after which time they seek access to other dementia carers, but only when the time was right for them. This offered the opportunity to develop new meaningful connections where they were able to provide or receive various forms of social support, positively impacting on their caring experience. Accessing options such as dementia support groups or relevant online blogs offered carers the opportunity to access social support which could also be shared with their loved one with dementia. This meant that their valuable time was not eroded by activities which did not aid their ability to provide care. For those with diminished social network members who could not rebuild this, health care professionals had an important role in providing interventions such as medications or counselling. Therefore, social support for familial carers is a valuable resource required to assist them in their caregiving journey.

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Chapter Two: Empirical Paper

“We live with the diagnosis”: a qualitative exploration of resilience in couples living with young onset dementia.

Louise Sheppard

Department of Clinical Psychology, University of Liverpool, Liverpool, United Kingdom

For correspondence:

Louise Sheppard

Department of Clinical Psychology

Eleanor Rathbone Building

74 Bedford Street

Liverpool

L69 7ZA

Tel: 0151 7945530

Email: l.sheppard2@liverpool.ac.uk

Abstract

Objective: To explore the experiences of cohabiting couples, where one person in the couple had a diagnosis of young onset dementia, using the ecological resilience framework (Windle & Bennett, 2011).

Methods: Semi-structured interviews were completed with five couples. Ecomaps were generated to triangulate responses, A constructivist grounded theory approach was selected to aid development of the ecological resilience framework, focusing on the experience of couplehood.

Results: Couples attempted to maintain their pre-dementia lives and routines but also acknowledged the impacts of dementia. Facilitating and hindering factors were found for all levels of the framework (couple, community, and society). Facilitators included the use of humour and social support from friends, peers, and family. Hindering factors included prognosis information and lack of young onset dementia-specific support. Moderating factors were also considered.

Conclusion: The ecological resilience framework was developed through the lens of couplehood, highlighting the couples' experience of living with dementia together. Utilising a resource-based approach to living with young onset dementia highlights numerous avenues to consider when supporting people to live well following diagnosis. Implications are discussed for all levels of the framework.

Keywords: resilience; young onset dementia; grounded theory; ecological framework; couplehood

Introduction

Young onset dementia (YOD) is a term used when an individual is diagnosed with dementia prior to their 65th birthday (Werner et al. 2009). Researchers have predicted that of the 850,000 people with a dementia diagnosis in the UK, 5% of those will have YOD, equating to approximately 42,000 people (Prince et al., 2014).

In contrast to the more usual profile of symptoms seen in early stages of dementia, where memory problems are the primary concern, symptoms which initially present can include impairments in executive functioning, motor abilities, or language production (O'Malley et al., 2021) making diagnosis more complex. Difficulties with diagnosis impact on the ability to determine prevalence rates (O'Malley et al., 2019) which in turn impact on the provision of services to support those with YOD (Hendriks et al., 2021). Diagnosis may often take longer to achieve compared to older adults (Werner et al., 2009), partly due to the broad range of symptoms (Baker & Butler, 2016) but also as individuals can be misdiagnosed with a range of other conditions such as bipolar disorder (O'Malley et al., 2019), particularly when presenting with characteristics of frontotemporal dementia (Tsoukra et al., 2022).

People with YOD and their loved ones face unique stressors as the dementia arises at a point during their lifespan when they are more likely to be actively involved in their careers or family life (Grunberg et al., 2021). Individuals living with YOD have described feeling isolated and have expressed fears around financial implications, such as retiring early or needing to continue to support dependant family members (Johannessen & Möller, 2013). People with YOD also report experiencing grief and loss as they attempt to alter their expectations for their life following a diagnosis (Grunberg et al., 2021).

Generally, in dementia care, family members often transition into an unpaid caring role to support their loved one (Zhou et al., 2021). Carers are often a child supporting their parent (40%), or spouses or romantic partners (26%; NHS Digital, 2010). Romantic partners

and spouses report a sense of loss, either through an emotional connection with their partner or by forgoing elements of their lives to provide this caring role (Bruinsma et al., 2022). On an individual level, carers frequently report experiencing a negative impact to their self-esteem as a result of their caring role, as well as high levels of burden (van Vliet et al., 2010).

Burden has often been researched in carers of a loved one with dementia. For example, carers may feel strained by their work commitments and caring responsibilities (Bakker et al., 2013). Perceived burden affects carer's mental health which impacts on the care they feel able to provide (Lloyd et al., 2019)

Not all individuals respond to stressors in the same way, i.e., by experiencing negative outcomes (Denckla et al., 2020). Furthermore, not all carers identify with the use of the word 'burden' to describe their experiences, as this indicates caring is wholly negative (Dementia Engagement Empowerment Project, 2014). Carers can cope well or adapt to the caring role (Kramer, 1997a), and feel satisfied in being able to care for another person (Ong et al., 2018). Research into burden or the challenges of caring has not explored why one carer experiences adverse impacts to health and general wellbeing whilst another does not. Additionally, interventions aimed at reducing burden in carers of a person living with dementia have produced small effect sizes (Zhou et al., 2021). Focusing solely on carer's subjective perceptions of burden neglects a consideration of factors external to the carer which could facilitate or hinder their coping ability.

There are alternative ways to conceptualise the responses of individuals following difficulties or changes in their lives. One of these is through resilience. Though there are debates about how resilience is defined, depending upon the context in which it is being investigated, there has been an increase in explorations of the mechanisms involved (Denckla et al., 2020). Traditional conceptions of resilience have focused on explaining this as personal qualities, influenced by personality characteristics such as extraversion or openness (Oshio et

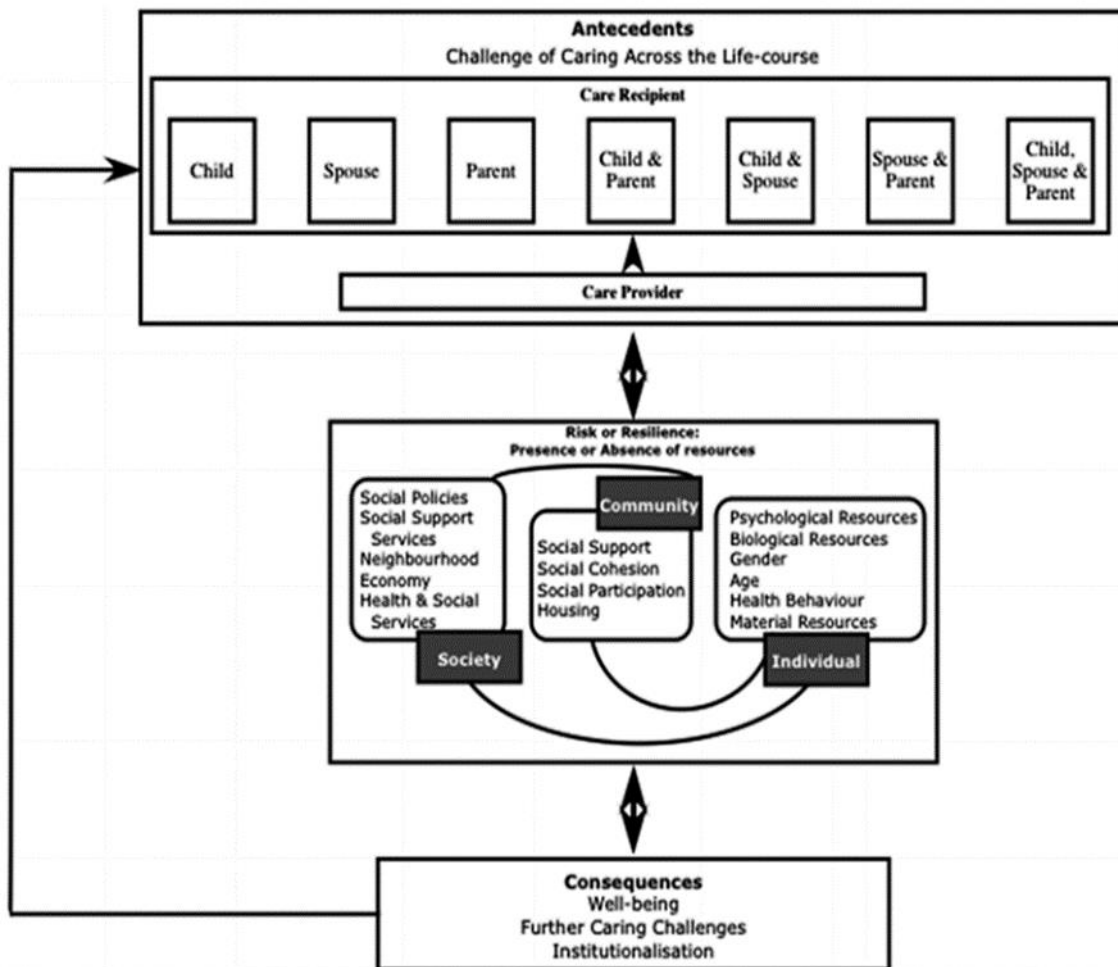
al., 2018). Others have hypothesised resilience as a dynamic process influenced by various factors such as the environment (Luthar et al., 2000).

Focusing on carers, Windle (2011) postulated the following definition of resilience:

The process of negotiating, managing, and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and “bouncing back” in the face of adversity. Across the life course, the experience of resilience will vary.

In the context of being a carer, resilience is an ongoing attempt to adapt to difficulties, impacted upon by factors within the individual but also through various external resources. Windle and Bennett (2011) postulated a framework of resilience to explore this definition (Figure 2). Their framework draws influence from Ecological Systems Theory (Bronfenbrenner, 1994), highlighting how carers have resources within their lives and around them (e.g., social support in their communities) which can foster resilience. Where there is limited access to resources, there could be a negative effect for the wellbeing of the carer, or on their experience of fulfilling their caring role (Donnellan et al., 2015; Whelan et al., 2020). Resilience is therefore not simply a trait that individuals have but can be influenced by external factors such as their social environments (Greve & Staudinger, 2006).

Figure 2. Ecological resilience framework (Windle & Bennett, 2011).



This ecological framework of resilience has been explored with carers of people living with dementia. Donnellan et al. (2015) interviewed carers, mapping their responses onto the framework. Those factors which facilitated resilience included maintaining relationships and the person with dementia’s identity prior to the diagnosis, as well as sharing their experiences with family and friends, and using societal resources such as respite care when required.

Research into resilience has typically focused on either the experiences of the carer or the person with dementia, with little focus on the interactions between the dyad. However, Molyneaux et al. (2011) explored this by asking dyads, where one person had dementia, about the strategies they implemented to maintain their relationship or sense of couplehood.

Couplehood has been defined as the feelings of belonging experienced by partners within a relationship (Kaplan, 2001). The relationship prior to dementia influences these feelings of belonging following the diagnosis (Wadham et al., 2016). The relationship was equally valued by both partners who jointly sought to sustain the relationship, particularly as the dementia diagnosis led to an increased amount of time spent together. Conway et al. (2018) also conducted dyadic interviews to explore resilience when one person in the dyad had dementia. They surmised that couples shared a definition of what it meant to be resilient.

By interviewing one half of a dyad, the other person's perspective is lost. When interviewing the person with dementia alongside their caring partner or spouse, resilience can be explored within the relationship's context, developing understanding of what it is like to live with dementia (Conway et al., 2018). Dyadic interviews promote the generation of ideas between the couple which can also support the person with dementia to feel included in the narrative that is shared (Grunberg et al., 2021).

Whilst the ecological framework of resilience (Windle & Bennett, 2011) has been researched within the field of dementia (Donnellan et al., 2015; 2019; Whelan et al., 2020) it has not been applied to those living with YOD, who may have additional difficulties to account for, such as caring for children or employment. Additionally, as the framework has only been considered from the perspective of the carer, any role the person with dementia may have in facilitating or hindering resilience is not clear, including how the couple jointly construct this understanding. It is also not obvious how these resources change or develop pre- to post- diagnosis.

The current study aimed to capture the experiences of cohabiting couples, by interviewing them as a dyad, where one person in the couple had a diagnosis of YOD. A constructivist grounded theory approach was chosen to investigate what factors facilitate resilience within the dyads, and then subsequently exploring the extent to which these factors

map on to the ecological resilience framework postulated by Windle and Bennett (2011). The framework was further developed with the additional consideration of couplehood and its effect on understanding resilience factors.

Method

Ethical statement

Sponsorship was obtained from the University of Liverpool (Appendix 9). Ethical approval was granted by North West – Greater Manchester East Research Ethics Committee and the Health and Research Authority (reference number: 21/NW/0179; Appendix 10) prior to participant recruitment.

Participants

Participants were recruited via an NHS trust site, a young onset dementia specific charity (Young Dementia Network), or via Join Dementia Research. Join Dementia Research is a National Institute of Health Research (NIHR) scheme to match people living with dementia and carers to appropriate research studies. Both Young Dementia Network and Join Dementia Research advertised the study on their websites.

If recruited via an NHS trust, participants were approached by staff working at this site who supplied the study's poster (Appendix 12) and participant information sheet (Appendix 13). The participant then contacted the researcher via email to express their interest. Staff were advised to make attempts at purposive sampling by identifying participants with a range of experiences related to their dementia to increase the heterogeneity of the sample and therefore the rigour of the research.

One couple were recruited via Young Dementia Network. An additional four couples did not match the inclusion and exclusion criteria so were not recruited. This couple were

asked if they could identify anyone in their social network who would meet the inclusion criteria (snowball sampling). This did not generate any additional participants who could be recruited.

Four couples were recruited via Join Dementia Research. Three of these couples initiated contact with the researcher. Over 60 profiles on Join Dementia Research were reviewed and contacted to share information about the study following subsequent ethical approval of an amended recruitment process. The fourth couple were recruited via this method.

Once a couple expressed their interest, the researcher sent the participant information sheet and arranged a time to meet the couple virtually for a 15-minute initial discussion which enabled participants to ask questions, and the researcher to check understanding and eligibility for the study. Consent was ascertained by exploring this understanding, and discussing any benefits or negatives to taking part, including a consideration of what would happen to their data.

Of the six couples identified via the NHS, five contacted the researcher to learn more about taking part. Two couples stated they matched the inclusion and exclusion criteria. One withdrew their interest following an initial meeting to discuss an interview. The second couple consented to their participation and were interviewed. Towards the end of their interview, they shared they were no longer a cohabitating couple. Therefore, their data could not be included in the analysis and write up as they did not fully meet the inclusion criteria. This decision was discussed thoroughly in supervision. Despite the unique perspective this couple brought, they could not be included due to the ethical approvals obtained for this research.

Participants were recruited via convenience sampling. For grounded theory, theoretical sampling should also be employed to explore newer elements of the emerging

analysis (Charmaz, 2014). The fifth couple who were excluded from the analysis were recruited via this method to elucidate data regarding future planning.

The study closed to participants as no new significant codes were identified during analysis.

Inclusion and Exclusion Criteria

To be eligible for the study, one person in the couple had to have received a diagnosis of dementia prior to their 65th birthday, and to have been diagnosed at least six months prior to the interview. The couple had to be living together and had to have been a couple for at least three years. For the person with YOD, they needed to be able to provide their own consent to take part in the study. As interviews were being held online, participants required access to a device with a microphone and webcam, as well as a stable internet connection. Participants were also required to have an adequate verbal ability to actively take part in an interview.

Couples were excluded from participating if the partner without YOD experienced their own cognitive difficulties. For any couple who did not meet the inclusion criteria, the researcher carefully explained why and thanked them for their interest. For those who did, a date and time for the interview was arranged, at least one week following the initial meeting.

A total of six couples were interviewed; however, the following excludes data from one of these couples. Therefore, the analysis reflects data collected from five couples. Participant characteristics are detailed in Table 5. Pseudonyms chosen by participants are used in place of their names.

Table 5. Participant demographics.

Pseudonym	Age	Partner with YOD	Length of Time in the Relationship	Time Since Dementia Diagnosis
John & Vicky	57 & 48	John	25 years	3 years
Ken & Angela	60 & 55	Ken	29 years	14 Months
Shane & Mary	58 & 58	Shane	39 years	14 Months
Basil & Sybil	60 & 53	Basil	32 years	3 years
Fred & Wilma	57 & 64	Wilma	27 years	2 years

All participants identified as White British, and all were in a heterosexual relationship. Four men and one woman had a diagnosis of YOD. Each couple had been together between 25 and 39 years (mean = 30.4 years) and had been diagnosed with dementia between 14 months to 3 years previously (mean = 25 months). All participants had retired following the dementia diagnosis, apart from Vicky (couple one) and Sybil (couple four) who reduced their working hours to help support their partner.

Data collection

Each interview occurred on an online video platform (Zoom) and followed a semi-structured schedule. Interviews were audio recorded to permit transcription and analysis. Interviews lasted between 63 minutes to 123 minutes.

The interview included questions to gather demographic information, experience of life before the dementia diagnosis (e.g., describe a time when you had to cope with a difficulty or overcome a challenge in your relationship), life following the dementia diagnosis

(e.g. what changed for you both afterwards), and ecomapping at two stages (when considering life prior to dementia as well as following the diagnosis).

Ecomaps have been employed in research with people with dementia (Fletcher, 2019) and in family caregiving (Rempel et al., 2007). This tool illustrates relationships and communities an individual is involved in, as well as aiding triangulation of data when used alongside interviews (Manja et al., 2021). An anonymised example of a completed ecomap is included in Appendix 14.

The interview schedule evolved at two time points (Appendix 15). Once following the first interview to decrease the number of times participants were asked to construct the ecomap (from three to two), and again following interview four to explore additional constructed themes.

Member checks were implemented. All couples consented to receiving a copy of their ecomap once complete. Four couples consented to receiving a transcript of their interview for feedback and to check for accuracy. All participants expressed approval of the content. They did not provide any additional comments.

Data analysis

A constructivist grounded theory (CGT) approach was implemented, first developed by Charmaz (2000), stemming from Grounded Theory (Glaser & Strauss, 1967). This analytical method aids generation of a theory about social processes using inductive and iterative investigation (Charmaz, 2014). Themes generated via the CGT method do not solely describe these social processes but interpret them, whilst acknowledging interactivity between each theme (Charmaz, 2014).

Since its initial inception, grounded theory has undergone epistemological developments away from its positivist paradigm roots (Rieger, 2019). CGT is one such development. CGT follows the methodological procedure instructed in the traditional

grounded theory approach, allowing for the development of theory grounded in data (Charmaz, 2000). Where it diverges is through incorporating aspects of the researcher such as their values or experiences, into the analytical process (Mills, Bonner & Francis, 2006), therefore adding a constructivist lens to the research process (Charmaz, 2014).

CGT was considered the appropriate analytical method for this study as, in addition to acknowledging the prior knowledge of the researcher, CGT also allows for recognition of existing models or frameworks and has been used as such in prior research such as Donnellan et al. (2015). Traditional grounded theory approaches do not consider the assumptions already held by researchers (Charmaz, 2000). As those in the research team had either clinical or research experience with dementia and carers, CGT was deemed the most applicable methodology, allowing for the influence of these experiences to be considered from development of the interview schedule through to data analysis and interpretation (Appendix 11 for reflexive statement).

The first two interviews were transcribed by the lead researcher to begin the process of data immersion. The remaining three were transcribed by a university approved transcription service. Transcripts were added to QSR's NVivo 12 (released March 2018) to aid analysis. Each interview was read multiple times and reviewed line-by-line to generate initial codes. Participant summaries were completed following interviews, focusing on individuals within the couple as well as the interactions between the couple. Summaries included a visual diagram to depict constructed narratives (Appendix 16).

Participant recruitment, memo writing, and initial coding occurred simultaneously. Following interviews one and two, more time was devoted towards participant recruitment, detracting from the analytical procedure at this time point. Without this time dedicated towards recruitment, there would not have been subsequent data to analyse. At this point,

Join Dementia Research was added as a recruitment site to widen the pool of participants to recruit from.

Initial codes were compared between each interview and new codes were generated when appropriate. This process allowed for the development of the interview schedule, such as exploring participants' thoughts around future planning. Memo writing was utilised throughout the process of code creation, as well as following each interview.

Several steps were taken to ensure rigour and trustworthiness throughout the analytical process. Research supervision occurred frequently during analysis which aided analytical thinking and code development. A subset of the data was analysed independently by supervisors and brought to supervision for discussion. A diary of memos was kept which was regularly referred to and considerations from this were utilised when developing later stages of coding.

The ecological resilience framework aided axial or focused coding, such as what could be identified as individual, community or societal resources present or absent for each couple. Initial codes which did not fit into axial codes were also recorded (see Appendix 17 for a list of codes).

Focused codes were amalgamated into selective codes through review of the data and discussion with supervisors to identify resources which facilitate or hinder resilience. Memos created throughout the data collection process were also considered during this process. The generated ecomaps allowed for a more in-depth view of community and societal resource levels deemed important by participants.

Attempts were made at theoretical sampling following the initial interviews and code creation. Once Join Dementia Research was added as a recruitment site, ethical approval was amended to allow for the researcher to initiate contact with potential participants via email rather than wait to be contacted. Responses to this study advertisement were few. However,

those who did respond shared how they met the criteria for inclusion. From this, couple six were recruited. They did not have children, which was an area of interest the coding was leading towards (i.e., children as a moderating factor). As all participants did have children, couple six were recruited for an alternative perspective.

Results

The following analysis builds on and further develops the ecological resilience framework by applying this to dyads living with YOD, further developing the original framework viewed through the lens of couplehood. Each level of the framework interacts with resources within that level as well as additional levels, therefore they are not experienced in isolation.

Participants also referred to resources utilised as individuals in their own right. These are not discussed here as this study aims to consider factors relevant to cohabiting couples, exploring the interaction between the individual and the couple they are in where applicable. These individual factors have been reported elsewhere (e.g., Hanna et al., 2021).

A total of 356 initial codes were generated across five interviews in an inductive process, grounded in the lived experiences of participants, developed through the collection of data and analysis through levels of coding. Per couple, initial codes were amalgamated via axial or focused coding under each level of the framework (Appendix 18 for an example), condensing this number of codes further. Codes were then compared across couples. See Appendix 17 for a full list of codes, many of which were lost between stages of coding.

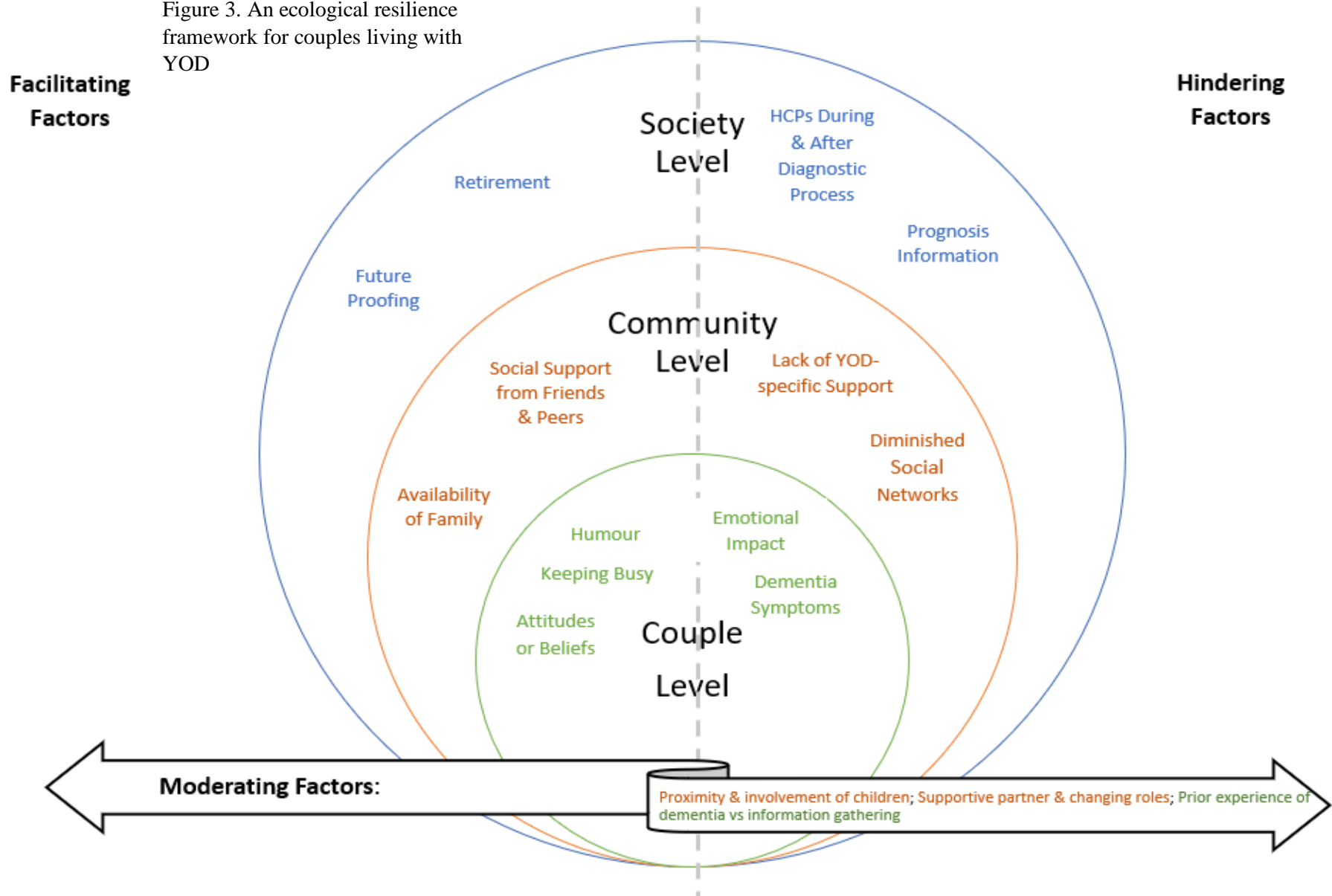
Figure 3 shows the developed ecological resilience framework, depicting resources deemed most applicable across cohabiting couples living with YOD. The model was developed through discussion within the research team and an iterative review of the data. The individual level suggested in the original framework (Windle & Bennett, 2011) was

renamed the couple level to further clarify these are resources found within couples, not individuals within each couple.

Subthemes were found for each of the three levels of the framework. For theme one, the couple level, subthemes incorporated humour, keeping busy, and attitudes or beliefs as factors which facilitated resilience. The emotional impact and dementia symptoms were hindering factors. For theme two, the community level, social support from friends and peers and the availability of family were facilitating resources. Lack of YOD-specific support and diminished social networks hindered feeling resilient. At the third level, society, future proofing and retirement aided resilience, whereas health care professionals and prognosis information negatively impacted on feeling resilient. To maintain resiliency, couples drew on resources from different levels. Additionally, resources interacted at different levels of the framework, further bolstering or hindering feelings of resilience.

There were also factors which contributed towards resilience to an extent, at which point they became hindering (see moderating factors). At the couple level, this included couples' prior experience of dementia versus information gathering. At the community level, this theme included the subthemes of proximity and involvement of children, and supportive partner and changing roles. Moderating factors were not found for theme three, referred to as the society level.

Figure 3. An ecological resilience framework for couples living with YOD



Couple Level

Hindering factors

Dementia symptoms. YOD was noticeable in all areas of life as it effected memory, vision, and speech production. A loss of independence was keenly felt as a result, due to adaptations required, interpreted as needing to surrender to dementia: ‘I do get frustrated with Fred and I’ll say “I want to be able to do this. I want to go and see...” “But you can’t.” You can’t (Wilma).’

Couples continually underwent a process of negotiation to identify how best to handle the changes occurring in their lives. Dementia symptoms created a power imbalance where couples strived to maintain elements of self which existed prior to the diagnosis. Those without dementia adapted by promoting their partner’s identity through maintaining their pre-dementia activities and routines as much as possible (see facilitating factors for further commentary).

The emotional impact of dementia. Couples referred to the shock of being informed their difficulties were due to dementia. Couples expected that there was ‘something wrong’ but dementia was often their last explanation for this, often due to the age of the person: ‘It’s still quite a shock. You don’t expect that sort of thing, especially when you’re 55 years old (John).’

Adapting to YOD was a continual adjustment process. The emotional impact was felt throughout the couple’s lives, either via low mood or anxiety, which was not present prior to the diagnosis. Therefore, YOD brought new difficulties into couples’ lives, further testing their resiliency: ‘You see people suffering from anxiety and you think, “Oh, what is that?”’

Well, I know exactly what that is now... (Shane).’ ‘He worries about the most stupid things. He really does (Mary).’

Couples pre-empted changes they could experience in the future, further adding to feelings of anxiety, preventing them from engaging in meaningful occupation (e.g., visiting friends). This reduced access to resources which helped to maintain emotional wellbeing considered at multiple levels of the framework.

Facilitating factors

Attitudes or beliefs. Couples considered their responses to adversities to fall within their internal locus of control. Couples did not deny that living with dementia was difficult. Instead, they initially allowed themselves time to process the information, and then incorporated this into their day-to-day life in a process of adjustment:

‘You can feel sorry for yourself, but it won’t do you any good... You just get on and make the best of it (Basil).’

‘I then wait and see what Basil’s reaction is going to be... what I’ve then got to change to make sure life is ticking along and his life has not got any less quality in it (Sybil).’

Partners without YOD felt responsible for supporting their loved one to continue to adapt to dementia’s progression over time. They adopted a task-oriented approach to help their partner with YOD, particularly when it came to navigating health care systems and professionals or the legalities of creating a financially secure future.

Keeping busy. Couples occupied their time in meaningful ways following medical retirement or reducing their working hours to support their partner. By keeping busy through hobbies or being an active part of family life, this enabled a sense of normality by

maintaining pre-dementia routines. Therefore, continuing with their life as it was pre-diagnosis was important to couples, as they deemed this as an indication that they were coping.

Keeping busy protected self-esteem by reminding couples that dementia had not diminished all their abilities, or by providing a distraction from low mood. For some, if left with too much idle time, this negatively impacted upon them as it gave them time to think about their changing circumstances:

‘When I’m on my own is when my head starts going, so I’d quite often turn up [to work] and I’d be a bit upset because I had time to think. You just get on. You get on with it when you’ve got other things to distract you (Sybil).’

Creating a routine was helpful for couples, particularly for the partner with dementia, as it created an awareness of what to expect without relying on short-term memory. Therefore, a way of coping with difficulty was to maintain or develop their involvement in activities, positively impacting on their emotional wellbeing.

Humour. A significant way of coping or approaching difficult situations was by utilising humour: ‘they refer to it up here as a work your ticket type of attitude... I will find humour in anything (Fred)’.

A sense of humour was viewed as a personality characteristic which also existed prior to the dementia diagnosis. Laughter became a tool to minimise distress or reduce tension. It enabled couples to find the positives in their situation, as well as maintain their evolving relationship through the use of shared humour.

Moderating factor

Prior experience of dementia vs information gathering. Previous experiences or knowing people with dementia via their social networks was helpful as this provided an idea of what to expect in the future, or signposted couples to appropriate first steps following diagnosis if they were task orientated. Discussed further at the societal level, when initially diagnosed, couples were provided with little information specific to YOD. Couples had to gather their own information to fill this gap, either via social network contacts or the internet: ‘Because you do not know anything about it, you think the worst straight away. You read too much. You look at too much... (Shane).’ ‘Oh, I was on the internet every minute – (Mary)’ ‘I looked at it at first and I thought, “it is too early...” (Shane).’

By having to find and develop their own knowledge of YOD, couples were at risk of overwhelming themselves, particularly when this occurred following initial receipt of the diagnosis. Couples felt they required some information, but it was difficult to determine how much was too much until it was too late.

Community Level

Hindering factors

Diminished social networks. Partners with YOD had reduced social network members outside of the family, either through lack of access due to retiring (see societal level) or due to friends’ fear of dementia:

‘They just didn’t come around anymore, did they? It was quite sad actually... they’d been friends 30, 40 years... (Vicky).’

‘[They] don’t realise there is sort of like a start and a middle, or a mild and a moderate like, and it kind of scared them off (John).’

A reduction of this resource meant fewer opportunities to utilise friendships as a coping mechanism, through the generation or receipt of social support, negatively affecting the person's emotional wellbeing.

Partners without YOD had maintained pre-existing relationships generated outside of their occupation. However, the nature of these relationships had altered, with more of a focus on how the person was coping with their increasing caring role, or instead maintaining contact via the phone due to time constraints imposed by caring or Covid-19. Whilst meeting with friends was of benefit to the partner without YOD, it also served as a reminder of what the person with YOD had lost. Time spent together as a couple increased, or the partner without YOD invited their loved one to spend time with their friends. This reduced the time spent focusing on the wellbeing of the partner without YOD where this occurred.

Lack of YOD-specific support. Couples discussed the minimal YOD-specific support they had access to (see societal level). Those with YOD wished to find others in a similar position: 'For me, just talking to people with dementia, just to understand what the impact's had on them... we've not done any of that... even though it's now well over a year since I've been diagnosed (Ken).'

Couples did not have opportunities to connect with others living with YOD. Whilst not all wanted this, for those who did it was viewed as a detriment. Even when there were opportunities to connect via support groups or information sessions, these were aimed more generically towards people living with dementia rather than YOD. Couples felt this was not specific enough to support them, leaving them feeling patronised, so they did not attend.

Where pre-existing YOD support groups were in place, they were mainly attended by staff members who imposed the content of sessions on attendees rather than generating this with them. Those with YOD who did attend were in the later stages of the dementia and less able to take part. Couples came away feeling invalidated and fearful of their future.

Therefore, there was a mismatch between the couples' needs and the resource on offer which prevented them from engaging as it detrimentally impacted upon feeling resilient.

Facilitating factors

Social support from friends and peers. For those who had access to this, couples expressed the significance of speaking with those who were in a similar position to themselves. For those who had lost friendships, finding peer support gained importance as those also living with dementia could answer questions, provide advice, or validate experiences. For the person with YOD, it felt easier to talk to a peer rather than their partner: '... about really personal stuff...they know exactly what's going on... I always find that talking to somebody who's in a very similar situation seems to help (John).'

Partners without dementia who had maintained their pre-existing friendships found these relationships valuable in having time for themselves, away from dementia. Friends provided social support, depending on the need expressed at the time. However, partners without YOD also valued the support gained from others in a dementia-related supporting role or social network members with medical knowledge. Access to knowledgeable others provided opportunities for learning, reflection, and validation. These benefited the couples' relationships either through respite from each other, or through the application of their new knowledge to their situation.

Availability of family. Even though couples weren't always in regular contact with family, knowing they were available either remotely or in person felt enough to support them: '...our son ... he's not as involved with us but it's still good to see him... (Ken)' '...they usually come here... most Sundays they come here at some point (Angela).

Maintaining pre-dementia routines which existed outside of employment was an important factor in promoting normalcy. Talking with, visiting, or having an active role in

family life was key to this, though on the couple's terms. Those who had pets also viewed them as part of the family. Pets were an important aspect in encouraging routine, ensuring that couples keep busy by promoting activity.

Moderating factors

Supportive partner and changing roles. Couples felt well supported by one another. The person with dementia expressed gratitude towards their partner who they viewed as resourceful problem solvers who promoted their involvement in activities and tasks they were previously involved in.

Since retirement, the amount of time spent with one another increased, providing additional opportunities to enjoy time together. However, couples also recognised a loss of independence for the person with dementia, and an increase in time spent checking on them. Additional time together also meant increased opportunities to feel frustration and impatience with one another. Where this occurred, it was often in relation to symptoms of dementia (interacting with the couple level), leaving both parties to feel guilty towards the other. This led to a consideration of the roles in which each person in the dyad held and how these had changed following the dementia diagnosis:

‘I think one of the difficult things for Shane as well is releasing things... You have to practice things in order to get better at them, but he does not give me the chance (Mary).’

‘You do not want to think you cannot do a basic thing... (Shane).’

‘Well, there are times, Shane, when you cannot, love. Or you can, but it needs to be checked... you need to share, is what I am saying (Mary).’

The person with dementia needs to feel ready to relinquish elements of their previous role to enable their partner to support them. This was experienced as a reminder of the impact of dementia on their lives, negatively affecting their mood.

Proximity and involvement of children. Four of the five couples had children, the majority of which had moved out of the family home and entered their own relationships, increasing the overall social network of the couple. Some had their own children, making the couple grandparents, a role which was cherished.

When initially diagnosed, couples kept the dementia diagnosis to themselves, to protect their children from distress. However, the secrecy was difficult to maintain. Once children were aware of the diagnosis, couples found it helpful to involve them in learning about dementia. This became a shared activity, promoting the strength of their relationship. However, it was sometimes difficult for children to have the same level of understanding or patience as the partner without YOD appeared to display: ‘They try not to get cross with him, but they leave the room. “I’m going to kill him, I’m going to kill him,” sort of thing (laughs). But it’s keeping him [Basil] involved, so we just keep going (Sybil).’

The partner without YOD received the brunt of the frustration as children aimed to protect their parent with YOD from this. The partner without YOD also kept this hidden from their loved one, and were left trying to minimise the distress of their child.

Societal Level

Hindering factors

Health care professionals during and after the diagnostic process. Numerous medical professionals were involved when diagnosing YOD. Whilst receiving a diagnosis was a

shock, this outcome was also partly expected due to the length of time taken and the numerous tests involved.

Receiving the diagnosis developmentally earlier than expected left some to feel they were a problem for services:

‘I got the impression that this second [consultant] was thinking, “he is a burden” (Shane).’

‘A drain on resources if you are diagnosed early (Mary).’

‘... “He should not have been told this early. He could have been left and he would not have been a drain on the service for maybe another four or five years” (Shane).’

This belief was reinforced by the limited support on offer for those with YOD, leaving couples unsure of when to approach services for help, or what could be offered to them other than medications. When accessing health care for ailments unrelated to dementia, health care professionals without YOD knowledge would question why a younger person had been diagnosed with dementia. This left couples in a position of having to prove why and how they lived with dementia. This was invalidating to both members of the couple who felt disbelieved or wondering if they too should question the YOD diagnosis.

Prognosis information. At the point of diagnosis, couples felt they were provided with too little information to support their understanding of dementia and their future. Couples had to seek their own information which could be overwhelming. An important part of this unspoken conversation with health care professionals concerned the prognosis: ‘I do not know if Wilma is going to die tomorrow, or in 10- or 15-years’ time, or in 20-years’ time. I have not got a bloody clue, because nobody has told us, or set any expectation (Fred).’

By not having these conversations, couples were left unable to plan for their futures with certainty, including when the partner without dementia may need to consider sourcing additional care. They were left concerned for a future they could not plan for.

Facilitating factors

Retirement. By leaving the workforce earlier than expected, couples gained access to their pensions, providing ongoing financial stability. It also enabled those with stressful occupations to leave earlier than anticipated. This interacts with the community level, as couples began to spend more time together, as well as adapt and bring forward plans for retirement. Adaptations occurred to incorporate dementia, but also due to Covid-19 restrictions: ‘... when we both said we were retiring, it was like, “oh, we’re going to have lots of lovely holidays...” We have had some lovely holidays but not the ones that we thought we’d have (Angela).’

Traveling was often the focus of their retirement plans, something which couples often did prior to dementia, offering periods of normality and respite from their altered futures.

Future proofing. It felt constructive for couples to pursue legal avenues upon receiving a diagnosis as a way of securing the future of the partner without dementia: ‘Heaven forbid, I even started looking at pensions, wills and all that kind of garbage. Just because perhaps it is the time to do so (Fred).’

It was important for the person with dementia to know that their partner would be protected financially through creating a will or signing over their property. It felt equally important for the partner without dementia to implement legal systems such as a power of attorney to ensure they had an active role in supporting their partner throughout the dementia

journey. These legalities helped couples develop feelings of control over an uncertain disease progression.

Discussion

The current study served to build on and develop Windle and Bennett's (2011) ecological resilience framework for couples living with YOD, addressing a gap in the literature by focusing more specifically on couples as well as YOD. Prior research has only considered resilience resources from the perspective of one half of the dyad (e.g., Donnellan et al., 2015), and dementia diagnosed after the age of 65. However, dementia is a shared experience between couples (Davies, 2011) and it is helpful to consider it as such.

This developed framework focusses on resilience rather than taking a deficit approach as existing literature has done. By considering resilience from an ecological standpoint, resources have been identified which facilitate or hinder resilience, offering couples and those who support them different avenues to consider.

By interviewing cohabiting couples, a methodologically innovative approach, rich narratives were derived, allowing for an investigation of resilience from multiple perspectives: the person with dementia, their partner, and the couple as a unit. During analysis, codes were homogenised, following a similar methodology to existing dyadic research (e.g., Molyneaux et al., 2012). Interviews were conducted during the Covid-19 pandemic, allowing for a unique exploration of the removal of certain resources, further testing resilience (e.g., contact with family and friends).

Couples attempted to maintain their pre-dementia lives as far as possible by utilising different resources, providing evidence for resilience. Whilst some of these resources were pre-existing (such as humour or the relationship) there were new ones to draw upon (such as peers or access to a pension). The evidence for moderating factors supports the hypothesis that resilience is a dynamic process, further evolving the ecological resilience framework

which did not report on factors which initially facilitate resilience but then become hindering at a certain point.

At the couple level, qualities such as humour and a person's beliefs or attitude contributed towards resilience. Humour has been shown to help maintain a person's identity and feelings of control (Clarke & Irwin, 2016). Couples indicated humour existed prior to YOD. However, they also noted an increase in utility following the diagnosis. When shared between a couple, humour aided continuity of a shared identity, eased tensions, and was often employed as a response to the difficulties posed by dementia (Hickman et al., 2018). Existing literature has shown humour to have a role in coping with emotional distress for couples living with dementia (Wadham et al., 2016). Couples living with YOD have emphasised the use of humour in promoting the strength of their relationship, increasing their ability to form a team against YOD (Bannon et al., 2022).

Couples coped with the difficulties posed by YOD through keeping busy; continuing routines or tasks that were important prior to their diagnosis, producing feelings of normalcy which bolstered self-esteem in the face of changing symptoms. It also served as a distraction from difficult emotions (a hindering factor at the couple level). Previous research has reported that people with YOD use coping strategies such as avoidance to provide relief from dementia symptoms, difficult emotions, and the impact of changes in roles within their couple (Bannon et al., 2021). The current study moves this finding forward as it does not solely focus on the person with YOD but also their partner. For example, if not kept busy, partners without YOD had time to ruminate, negatively impacting on their emotional wellbeing, potentially affecting the support they provide their partner. Therefore, partners without YOD also employ coping strategies such as avoidance of difficult thoughts and feelings.

Maintaining normalcy in dementia has been found elsewhere. Conway et al. (2020) interviewed dyads living with dementia. They defined resilience as efforts to maintain continuity, where couples adapted to how tasks were completed rather than which tasks were considered. Participating in activities is considered a protective factor against low mood or ruminating about YOD (Williamson & Paslawski, 2016) which can also serve to safeguard couples' relationships from the impact of negative emotions (e.g., arguments; Bannon et al., 2022). Additionally, engaging in meaningful activities serves as a reminder of what a person is still able to do when they have experienced loss in other areas (Roach & Drummond, 2014).

A person's prior experience of dementia alongside gathering information about the condition facilitated resilience to a point until they were considered hindering. Couples had little relevant information upon diagnosis, so sought this out independently, which could be overwhelming. Those who did not have access to an expert by experience, or had little prior knowledge of dementia, lamented the lack of information imparted to them at the point of diagnosis. This factor interacts with the societal level of the framework, i.e., the involvement of health care professionals. This finding contradicts previous research which reported that people are given too much information at the point of diagnosis. Additionally, people expressed a preference for emotional support rather than factual information following diagnosis (O'Malley et al., 2021), which was not conveyed in the current study.

At the community level, the availability of family as well as receiving social support from friends and peers facilitated resilience. When discussing familial relationships, couples appeared to instigate contact or visits. In Donnellan et al.'s (2017) study of older spousal carers of a person with dementia, carers kept family more distant compared to friends. Whilst familial support was valued by carers, they also appreciated their independence from them. This supports the current study.

The current study also diverges from existing research in relation to family support. Couples living with YOD who had dependents, i.e., children, valued involving them in learning about dementia once they had time to adjust to the diagnosis. Older children moved out of the family home to start their own families. This was a moderating factor, as the children could negatively impact on the resilience of their parent without YOD when they reflected on the symptoms present in their parent with YOD. Poole and Patterson's meta-ethnographic review (2022) indicated various psychological and practical impacts of a parent's YOD diagnosis on their children. These included children putting their lives 'on hold' to help support their parent. This was not found in the current study, with parents reporting that their children continued their lives as usual.

Social support needs changed following a YOD diagnosis. This finding is supported by previous research (e.g., Bannon et al., 2022). The loss of pre-dementia friendships, and lack of YOD-specific support, were considered hindering factors in the framework. Value was placed in seeking those in similar positions to learn from and share experiences. The partner without YOD more often reported continuing to receive social support from pre-existing relationships. It could be surmised that, as a resilience resource, social support serves different functions, i.e., emotional or instrumental (Kelley et al., 2017). In existing research, people living with YOD have highlighted the importance of community-based support (Mayrhofer et al., 2018). Resilience is facilitated when there is access to a resource which matches current need (Donnellan et al., 2017). The current study highlighted the limited YOD-specific community-based support couples could access; a finding not supported by Mayrhofer et al. (2018) who mainly reported on the impact for the person with YOD. The current study highlighted how couples wanted a space they could attend together, but also offered opportunities to spend time with those in a similar position, i.e., person with YOD or a person supporting their partner with YOD.

Also at the community level, the support received from partners was experienced as helpful, but it was also recognised that the roles held within the couple were in flux. This change served as a reminder of the losses incurred due to dementia symptoms, impacting on mood and self-esteem (couple level). The support provided by the partner was helpful in coping with this if it was not experienced as pushing the person with YOD to make changes before they were ready to. Similar findings have been explored elsewhere. For example, Molyneaux et al.'s (2012) interviews with couples, where one person had dementia, discussed the importance of couplehood. Couples endeavoured to preserve balance within their relationships following the diagnosis despite having to incorporate more of a caring role towards the person with dementia. A way of doing this was through sharing aspects of coping with dementia, such as voicing frustration towards the illness. This strengthened the relationship through uniting the couple against dementia.

Numerous hindering factors were noted at the societal level. Contact with health care professionals throughout the diagnostic process and afterwards negatively impacted couples. Additionally, the lack of information at diagnosis around prognosis had a lasting negative effect. Yates et al. (2021) conducted a systematic review exploring the disclosure of dementia diagnoses by health care professionals. Disclosures had a negative emotional impact on the person with dementia, their supporters, and the health care professional involved. Carers wanted to know more about prognosis, however doctors found this difficult to provide as they attempted to balance honesty with hope, despite carers wanting openness. O'Malley et al., (2019a) also considered the delivery of a YOD diagnosis. They highlighted that the experience of receiving a YOD diagnosis was significantly impacted upon by the language employed by health care professionals, such as the use of jargon or clinicians who were unable to hold the conversation with a calming demeanour. In the current study, couples felt a YOD diagnosis caused difficulties for services which they inferred through the manner or

language used by health care professionals during diagnostic or follow-up appointments. This has implications for how able people living with YOD feel to use the structures that are ultimately set up to support them.

There were facilitating resources at the societal level, but these were fewer in comparison to other levels. Retiring from work aided resilience through access to a pension and increased contact with significant relationships (community level) or valued activities (couple level). Completing legal processes such as creating a power of attorney or a will helped couples to plan for an uncertain future, allowing the person with YOD to support their partner at a time they may be less able to. Financial stability has been reported in previous studies. For example, access to monetary resources allowed for maintenance of lifestyles prior to dementia, including being able to afford holidays which could provide respite (Conway et al., 2020). This interacts with the couple level of the framework, allowing couples to engage in meaningful activities, occupying their time.

Strengths and limitations

Previous research has focused on the carer of the person with dementia. A strength of the current study's methodology was in interviewing dyads, allowing for multiple perspectives to be communicated while generating a shared understanding. Couples derive benefit from discussing difficulties together (Molyneaux et al., 2012). Exploring resilience following a YOD diagnosis allowed for this. This is the first study to the author's knowledge which explores this topic for cohabiting couples living with YOD.

This strength could also be considered a limitation. Interviewing dyads can introduce challenges such as one person in the pair offering more information than the other, the increased possibility of tangential responses, and participants being willing to engage in conversations which could result in disagreements, potentially rupturing the relationship (Szulc & King, 2022). By exploring difficult events and their impact as a dyad, members of

the couple may wish to appear more socially desirable through careful editing of their responses so as not to upset their partner (Conway et al., 2020). This has been noted in previous dyadic research, where couple's responses were indicative of their relationship style, e.g., one more articulate than the other (Molyneaux et al., 2012). In the current study, narratives were further developed as the person with YOD could be supported by their partner to recall their shared histories. Dyadic methodology lends itself to the generation of ideas during an interview, developing the quality of the data produced through the sharing of narratives (Morgan et al., 2013).

This method has been utilised elsewhere. Kvalsvik and Øgaard (2021) compared responses from individual interviews against dyadic interviews when recruiting older adults. They surmised that whilst individual interviews provided rich data on their topic, dyadic interviews resulted in an increased number of themes developed from the data, potentially due to a higher number of total participants recruited. They hypothesised this was also due to interview responses which included the views of the collective (i.e., the dyad) as well as the individuals within the dyad. However, respondents in individual interviews gave more personal information in comparison to the dyads. Only two of their eight dyads were cohabitating couples, so these conclusions were based on a range of relationship types, including strangers. Therefore, the use of cohabiting dyads in the current study may have minimised the risk of reduced openness from participants, as couples had been in their relationships for an average of 30.4 years.

The analytical process enacted constant reflexivity. Initial codes and the original data were revisited during the creation of further coding levels. The researcher's memos were consulted when selecting final coding. Levels of the framework were reviewed on multiple occasions during research supervision. The generation of ecomaps allowed for data triangulation which was of utility when considering the community and societal levels,

adding to the strength of this study. However, there was no involvement of experts by experience during the analytical process due to time constraints which would have improved rigour.

A key limitation was in the recruitment process. Efforts were made to introduce theoretical sampling, however, recruiting couples proved difficult. Various attempts were made to expand the number of recruitment sites to reach more people with YOD. However, being interviewed as a dyad may have been daunting. Additionally, interviews were conducted via the internet, automatically excluding those could not access this resource. The number of couples recruited were fewer than anticipated despite efforts to increase accessibility of the research.

Those who were recruited could have been considered more resilient than those who did not wish to take part as they were actively seeking out research opportunities. Additionally, even though recruitment was nationwide, all participants were White British. Therefore, the perspectives of other cultures have been missed. Furthermore, in most couples, it was men who were diagnosed with YOD. This does not represent those who develop dementia in their lifetime (65% women; Prince et al., 2014). However, grounded theory approaches try to identify important categories for consideration rather than aim to be generalisable across all people living with dementia.

Fewer resources were noted at the societal level in comparison to the couple and community levels. This may reflect the questions asked during the interview which did not draw out enough consideration of these resources. However, this has also been reported in previous studies (e.g., Donnellan et al., 2015). It may also be an impact of interviewing couples during a pandemic, where access to particular resources were diminished due to government legislation.

Clinical Implications

Utilising a resource-based approach exposes several areas to consider clinically. At all three levels of the framework, couples discussed the diagnostic process and access to information, including signposting to support in the community. Focusing on the societal level, health care professionals need to clearly inform people on the diagnostic pathway of what to expect and the time frame this could encompass, including a thoughtful consideration of the language they use to communicate a diagnosis of YOD. If indicated, pre-diagnostic counselling or information sessions would be useful, impacting on the couple level of the framework. Services should look to develop their post-diagnostic support offer for people with YOD, involving them in the process to ensure the support is relevant and suitable, supporting people living with YOD at the community level.

When supporting a person with YOD, their wider social network should also be considered (i.e., community level). Some will have less access to this for various reasons. Ecomapping is one useful tool to explore this at the point of assessment.

For those living with a partner who becomes their main supporter, clinicians may help them by discussing future changes due to the dementia and consider when they may require further assistance in their caregiving journey. Clinicians should not automatically consider a partner a 'carer' as this change of identity comes following adaptation.

If diagnosed with YOD, providing information around prognosis is important (discussed at the societal level). As it is a diagnosis with an emotional impact (see couple level), more than one session may need to be offered to discuss care planning. Putting this into clinical practice has implications for health care and social services who need to respond to growing demand (Alzheimer's Society, 2019). However, NICE guidelines for supporting people with dementia (National Institute for Health and Care Excellence, 2018) recommend utilising care co-ordinators, a named clinician within health care teams responsible for co-

ordinating care. This model has been implemented in dementia-specific services across the UK (e.g., Bristol Dementia Wellbeing Service, 2021). Even with supportive services in place, offering couples clarity regarding the prognosis of dementia remains difficult as the progression of dementia can be unique to each individual, making estimates of life expectancy variable (NICE, 2021).

During conversations with people living with YOD and their partner, clinicians could consider exploring coping mechanisms such as distraction techniques as these could become problematic, e.g., avoidance of problems which may cause difficulties in the future. This may be a helpful topic to explore during post-diagnostic support sessions, where people living with YOD can discuss this with their peers.

Psychological therapies to support low mood or core beliefs which impact on perceptions for the future may be indicated. Involving the partner of the person with YOD would be helpful, with consent. Dyadic interventions after diagnosis can support the communication styles used by couples when discussing the emotional implications of YOD (Wawrziczny et al., 2014). Individuals within the couple may face their own challenges so may benefit from separate therapeutic interventions, as suggested in NICE guidelines (2018). However, as indicated in the current study and elsewhere, some difficulties and concerns are shared between members of the couple and would be better supported by a couples-based therapeutic intervention, such as a consideration or development of coping strategies (Popok et al., 2022). Offering life story work post-diagnosis may help to promote the identity of the person with YOD, as well as the identity they share within their couple.

Suggestions for Future Research

Future research may look to develop the ecological resilience framework further. For example, an identified factor at the community level involved children. However, this would not be applicable to those who are childless. Families without children are increasing in

number, or those with children may not be in close proximity to them (Ageing Well Without Children, 2019). Research could consider what resources they may be more likely to draw upon.

The current study interviewed dyads who were romantic partners. Partners account for 26% of dementia carers, whereas children equate to 40% (NHS Digital, 2010). Therefore, research could investigate the framework with children who care for a parent with YOD.

The current study was cross-sectional, exploring resilience-related factors at one point in time. The study identified that the process of being resilient is dynamic and subject to influence at multiple levels (couple, community, and societal). Future research would benefit from a longitudinal approach to exploring resilience in couples living with YOD.

Conclusions

Factors which facilitate or hinder resilience were found for all levels of the ecological resilience framework initially hypothesised by Windle and Bennett (2011). The framework was applied to couples living with YOD, further developing the model through the perspective of couplehood. Some factors supported resilience, but only to a point where they then had a hindering effect, acting as moderating factors. The developed framework highlights numerous areas in which couples living with YOD can be supported to aid their dementia journey, helping them to have the best quality of life possible.

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Appendices

Appendix 1. Author Guidelines for Aging & Mental Health

Author Guidelines for Aging & Mental Health Journal

Aging & Mental Health is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Aging & Mental Health accepts the following types of [article](#): Review, Original Article.

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**Usage in 2018-2020 for articles published in 2016-2020.

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Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper.

A typical paper for this journal should be no more than 7,000 words for quantitative papers and 8,000 words for qualitative papers inclusive of

- figures
- tables
- references
- tables

Appendix excluded.

All revised papers could have extra 500 words allowance.

Style Guidelines

Please refer to these [quick style guidelines](#) when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'.

Please note that long quotations should be indented without quotation marks.

All revised papers should have a clean version.

If there is more than one corresponding author, please ~~unsubmit~~ the paper and visit [here](#).

[If there is more than one first author, unsubmit the paper.](#)

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[All clinical trials must have been registered in a public repository and trial registration numbers should be included in the abstract, with full details in the methods section.](#)

[If the manuscript does not follow the required reference style, please unsubmit the paper and visit AMH reference format guideline.](#)

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Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

[Word templates](#) are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact us [here](#).

References

Please use this [reference guide](#) when preparing your paper. An [EndNote output style](#) is also available to assist you.

How should I format my manuscript?

This guide contains advice to help you get started, but some journals will have specific layout and formatting requirements.

Before you submit your article, make sure you've checked the instructions for authors for your chosen journal, so you are aware of everything required. You can find the instructions for authors on the journal's homepage on [Taylor and Francis Online](#).

Below is a list of formatting considerations that are often specified by academic journals.

Font

Use Times New Roman font in size 12 with double-line spacing.

Margins

Margins should be at least 2.5cm (1 inch).

Title

Use bold for your article title, with an initial capital letter for any proper nouns.

Abstract

Indicate the abstract paragraph with a heading or by reducing the font size.

The instructions for authors for each journal will give specific guidelines on what's required here, including whether it should be a structured abstract or graphical abstract, and any word limits.

If you need further guidance, [learn more on how to write an effective abstract and title](#).

What is an abstract in a research paper?

This is your opportunity to 'pitch' your article to the journal editors, and later, its readers.

Your abstract should focus on what your research is about, what methods have been used, and what you found out.

Keywords

Keywords help readers find your article, so are vital for discoverability. If the journal instructions for authors don't give a set number of keywords to provide, aim for five or six.

Headings

This will show you the different levels of the heading section in your article:

1. First-level headings ([e.g.](#) Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.

2. Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.
3. Third-level headings should be in italics, with an initial capital letter for any proper nouns.
4. Fourth-level headings should be in bold italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.
5. Fifth-level headings should be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

Tables and figures

Show clearly in your article text where the tables and figures should appear, for example, by writing [Table 1 near here].

Check the instructions for authors to see how you should supply tables and figures, whether at the end of the text or in separate files, and follow any guidance given on the submission system.

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Do I need permission to reproduce a table?

It's very important that you have been given permission to use any tables or figures you are reproducing from another source before you submit.

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If you're submitting a [data availability statement](#) for your article, include it within the text of your manuscript, before your 'References' section. Remember to give it the heading 'Data availability statement' so that readers can easily find it.

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If you are preparing your manuscript in Microsoft Word and your article contains special characters, accents, or diacritics, we recommend you follow these steps:

- European accents (Greek, Hebrew, or Cyrillic letters, or phonetic symbols): choose Times New Roman font from the dropdown menu in the "Insert symbol" window and insert the character you require.

- Asian languages (such as Sanskrit, Korean, Chinese, or Japanese): choose Arial Unicode font from the dropdown menu in the “Insert symbol” window and insert the character you require.
- Transliterated Arabic: choose either Times New Roman or Arial Unicode (unless the instructions for authors specify a particular font). For **ayyū**s and hamzas, choose Arial Unicode font from the dropdown menu in the “Insert symbol” window. Type the Unicode hexes directly into the “Character code” box, using 02BF for **ayyū**, and 02BE for hamza.

Running heads and received dates

These aren't required when submitting a manuscript for review. They will be added during the production process if your article is accepted for publication.

Appendix 2. Email exchange regarding review topic.

Dear Louise

Thank you for your email and enquiry about Nicole's review, there are two completed reviews as the decision was made to differentiate between people living with dementia at home and in a care home

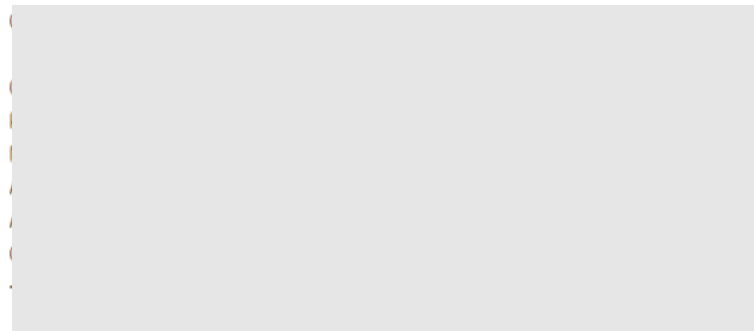
Headline messages from the review on the Social Networks of People Living With Dementia in Care Homes

- Twenty-four studies that spanned 20 years included.
- No agreed definition of a social network or its core characteristics.
- People living with dementia in care homes do experience friendships in care homes, but how the networks had changed post admission to care homes was unexplored.
- There is work on creating new networks for people with dementia admitted to care homes.
- The physical environment, proximity to others and staff involvement influenced the creation and maintenance of social networks.
- Eight studies collected self-report data from people living with dementia and four studies conducted a social network analysis of residents' social networks.

Both in draft format and will be submitted for publication once Nicole returns from maternity leave

Hope that helps

Best wishes



Appendix 3. Search Strategy.

1. dementia
2. Alzheimer*
3. unpaid
4. informal
5. care*
6. caregiv*
7. "social support"
8. famil*
9. friend*
10. relations*
11. interpersonal
12. interview*
13. "focus group*"
14. Qualitative

1 OR 2

AND 3 OR 4

AND 5 OR 6

AND 7 OR 8 OR 9 OR 10 OR 11

AND 12 OR 13 OR 14

Search example via PubMed July 2022:

History and Search Details						Download	Delete
Search	Actions	Details	Query	Results	Time		
#7	...	>	Search: #1 AND #2 AND #3 AND #4 AND #5 Filters: from 1000/1/1 - 2022/3/4	395	03:43:30		
#6	...	>	Search: #1 AND #2 AND #3 AND #4 AND #5	419	03:43:14		
#5	...	>	Search: ((interview*[Title/Abstract]) OR ("focus group*" [Title/Abstract])) OR (qualitative[Title/Abstract])	627,197	03:42:41		
#4	...	>	Search: (((("social support"[Title/Abstract]) OR (famil* [Title/Abstract])) OR (friend*[Title/Abstract])) OR (relations* [Title/Abstract])) OR (interpersonal[Title/Abstract])	2,872,800	03:42:16		
#3	...	>	Search: (care*[Title/Abstract]) OR (caregiv*[Title/Abstract])	1,994,136	03:41:26		
#2	...	>	Search: (unpaid[Title/Abstract]) OR (informal[Title/Abstract])	26,829	03:40:41		
#1	...	>	Search: (dementia[Title/Abstract]) OR (Alzheimer*[Title/Abstract])	256,320	03:40:20		

Showing 1 to 7 of 7 entries

Appendix 4. Inclusion Exclusion Criteria.

Parameter	Inclusion Criteria	Exclusion Criteria
Sample	<p>Familial carer of a person living with a dementia (may also be referred to as 'informal' carer but must be related to the person living with a dementia).</p> <p>Over the age of 18.</p>	<p>Articles which focus on the person living with a dementia rather than their familial carer</p> <p>Dyad-style data collection (<i>i.e.</i> interviewing both carer and the person living with a dementia)</p> <p>Papers which focus on or include participants who are not a familial carer, <i>e.g.</i> a health care professional</p>
Phenomenon of interest	<p>'social' &/or 'support' referred to in the aim/research questions (social support outside of the family following becoming a carer for their family member living with a dementia)</p>	<p>Studies which incorporate or focus on a specific intervention, <i>e.g.</i> pilot studies, therapies</p> <p>Studies which focus on the impact of involvement from health care professionals (<i>i.e.</i> not social support but rather professional or paid support)</p> <p>Studies which focus on or refer to Covid-19</p> <p>Studies which focus on loss of contact with family members</p>
Design	<p>Interviews (<i>e.g.</i> structured, semi-structured), focus groups</p>	<p>Statistical analysis</p>
Evaluation	<p>Themes exploring social support following the adoption of a caring role</p> <p>Emotional impact of loss of social support following a loved one's dementia diagnosis and the adoption of a carer role</p>	<p>No reference to social support</p> <p>Impact on those other than the familial carer (<i>e.g.</i> health care professionals)</p>
Research type	<p>Qualitative; published in a peer-reviewed journal</p>	<p>Quantitative or mixed methods; policy documents; dissertations</p>




Appendix 5. CASP Tool.



 www.casp-uk.net
 info@casp-uk.net
 Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

-  Are the results of the study valid? (Section A)
-  What are the results? (Section B)
-  Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
 - If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
 - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
 - If methods were modified during the study. If so, has the researcher explained how and why
 - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
 - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
 - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 6. Data Extraction Tool.

Area	Data
Author(s) Publication year Title of paper	
Aims of the research	
Participant characteristics (Including total number and any drop outs; gender; age etc.)	
Sampling approach	
Location When	
Methodology	
Analysis	
Outcome summary	

Appendix 7. Process of Code Generation for Thematic Synthesis.

Paper 1 – West & Hogan (2019)

19 codes (from most to least references):

- Wellbeing (15)
- Sharing (12)
- Information gathering (10)
- Belonging (8)
- Internal resource (5)
- Group stimulation (5)
- Change of environment (5)
- Supportive atmosphere (5)
- Social interaction (5)
- Right time (5)
- Worth their time (3)
- Knowledge of dementia (3)
- Activities (3)
- Needs of person with dementia (2)
- Additional responsibilities (2)
- Judgements or stigma (2)
- Stress (1)
- Opportunity (1) – same as social interaction
- Loneliness (1)

Code grouping:

- Wellbeing + stress + loneliness + group stimulation + activities + social interaction
- Sharing + information gathering + belonging + knowledge of dementia
- Change of environment + supportive atmosphere + right time + worth their time + needs of person with dementia + internal resource
- Additional responsibilities
- Judgements or stigma

Paper 2 – Parkinson et al. (2020)

7 codes (from most to least references):

- Loneliness (11)
- Wellbeing (2)
- Coping strategy (2)
- Stress (1)
- Change of environment (1)
- Sharing (1)
- Assumptions (1)

Code grouping:

- Loneliness + wellbeing + stress + sharing + change of environment
- Coping strategy + assumptions

Paper 3 – Gibson et al. (2019)

4 codes (from most to least references):

- Access (2)
- Wellbeing (1)
- Technology (1)
- Change of environment (1)

Code grouping:

- Access + wellbeing + change of environment
- Technology

Paper 4 – Orpin et al. (2014)

17 codes (from most to least):

- Access (6)
- Worth their time (4)
- Loss of contacts (4)
- Wider community (2)
- Responsibility (1)
- Opportunity (1) – same as loss of contacts
- Knowledge of dementia (1)
- Judgements or stigma (1)
- Worry without them (1)
- Wellbeing (1)
- Trust (1)
- Identity (1)
- Gatekeeping (1)
- Encouragement from others (1)
- Change of environment (1) – same as encouragement from others
- Activities (1) – same as encouragement from others
- Additional responsibilities (1)

Code grouping:

- Access + encouragement from others + wider community
- Loss of contacts + worth their time + judgments or stigma + identity + additional responsibilities
- Responsibility + gatekeeping + knowledge of dementia + trust
- Worry without them + wellbeing

Paper 5 – Nay et al. (2015)

27 codes:

- Difference or change (15)
- Loss (11)
- Loss of contacts (10)
- Adapting (9)
- Wellbeing (8)
- Judgments or stigma (8)
- Opportunity (7)
- Defining social participation (5)
- Activities (5)
- Access (5)
- Social interaction (4)
- On the carer's terms (4)
- Coping strategy (4)
- Identity (3)
- Group stimulation (2) – same as a previous code
- Finances (2)
- Change of environment (2)
- Wider community (2)
- Sharing (2)
- Knowledge of dementia (2)
- Avoidance (2)
- Information gathering (1) – same as a previous code
- Encouragement from others (1) – same as a previous code
- Technology (1)
- Internal resource (1)
- Belonging (1) – same as a previous code
- Additional responsibilities (1)

Code grouping:

- Difference or change + judgements or stigma + avoidance + opportunities + loss + loss of contacts + access + additional responsibilities
- Adapting + activities + social interaction + on the carer's terms + finances + change of environment + knowledge of dementia
- Wellbeing + coping strategy + identity + sharing + technology + internal resource
- Defining social participation
- Wider community

Paper 6 – Carpentier et al. (2008)

10 codes:

- Information gathering (4)
- Right time (2)
- Encouragement from others (2)
- Difference or change (2)
- Social interaction (1)
- Sharing (1)
- Wellbeing (1) – same as a previous code
- Supportive atmosphere (1)
- Internal resource (1)
- Coping strategy (1)

Code grouping:

- Information gathering + right time + encouragement from others + sharing + supportive atmosphere + coping strategy
- Difference or change + social interaction + internal resource

Paper 7 – Mackenzie (2006)

19 codes:

- Judgments or stigma (8)
- Loss of contacts (6)
- Wider community (3)
- Coping strategy (3)
- Social interaction (2)
- Encouragement from others (2)
- Difference or change (2)
- Belonging (2)
- Wellbeing (2)
- Trust (2)
- Loneliness (1)
- Information gathering (1)
- Supportive atmosphere (1)
- Sharing (1)
- On the carer's terms (1)
- Change of environment (1) – same as previous code
- Assumptions (1) – same as previous code
- Avoidance (1) – same as previous code
- Activities (1) – same as previous code

Code grouping:

- Judgements or stigma + loss of contacts + wider community + coping strategy + trust + loneliness + assumptions

- Social interaction + encouragement from others + belonging + information gathering + supportive atmosphere + sharing
- Difference or change + wellbeing + on the carer's terms

Paper 8 – Anderson et al. (2017)

12 codes:

- Technology (11)
- Wider community (5)
- Coping strategy (5)
- Information gathering (4)
- Supportive atmosphere (3)
- Access (2)
- Social interaction (1)
- On the carer's terms (1) – same as previous code
- Internal resource (1) – same as previous code
- Gatekeeping (1) – same as previous code
- Encouragement from others (1)
- Adapting (1)

Code grouping:

- Technology + wider community + access + adapting
- Coping strategy + information gathering + supportive atmosphere + social interaction + encouragement from others

Appendix 8. Which Papers Contribute to Themes.

Theme	Paper
A shrinking social world	2 - Parkinson et al. (2020) 4 - Orpin et al. (2014) 5 - Nay et al. (2015) 7 - Mackenzie (2006) 8 - Anderson et al. (2017)
Impact on wellbeing	1 – West & Hogan (2019) 5 - Nay et al. (2015)
Sharing as a way of caring	1 - West & Hogan (2019) 3 - Gibson et al. (2019) 4 - Orpin et al. (2014) 6 - Carpentier et al. (2008) 7 - Mackenzie (2006) 8 - Anderson et al. (2017)

Paper 1	Paper 2	Paper 3	Paper 4	Paper 5	Paper 6	Paper 7	Paper 8
<p>Impact on Wellbeing (Wellbeing + stress + loneliness + group stimulation + activities + social interaction)</p> <p>Expanding communities: sharing is caring (Sharing + information gathering + belonging + knowledge of dementia)</p> <p>A Process of Adaptation (Change of environment +</p>	<p>A Changing Social World (Loneliness + wellbeing + stress + sharing + change of environment)</p> <p>Coping strategy + assumptions</p>	<p>Sources of Support (Access + wellbeing + change of environment)</p> <p>Technology</p>	<p>Sources of Support (Access + encouragement from others + wider community)</p> <p>A Changing Social World (Loss of contacts + worth their time + judgments or stigma + identity + additional responsibilities)</p> <p>Gatekeeping (Responsibility + gatekeeping + knowledge</p>	<p>Meaningful Connections (Difference or change + judgments or stigma + avoidance + opportunities + loss + loss of contacts + access + additional responsibilities)</p> <p>A Process of Adaptation (Adapting + activities + social interaction + on the carer's terms + finances + change of environment</p>	<p>Sharing is Caring (Information gathering + right time + encouragement from others + sharing + supportive atmosphere + coping strategy)</p> <p>Developing a capacity to care (Difference or change + social interaction + internal resource)</p>	<p>An Inevitable Consequence (Judgments or stigma + loss of contacts + wider community + coping strategy + trust + loneliness + assumptions)</p> <p>Expanding communities: sharing is caring (Social interaction + encouragement from others + belonging + information</p>	<p>Expanding communities: sharing is caring (Technology + wider community + access + adapting)</p> <p>Connecting with others (Coping strategy + information gathering + supportive atmosphere + social interaction + encouragement from others)</p>
<p>supportive atmosphere + right time + worth their time + needs of person with dementia + internal resource)</p> <p>Additional responsibilities</p> <p>Judgements or stigma</p>			<p>of dementia + trust)</p> <p>Worry without them + wellbeing</p>	<p>+ knowledge of dementia)</p> <p>"A Person can only take so Much" (Wellbeing + coping strategy + identity + sharing + technology + internal resource)</p> <p>Defining social participation</p> <p>Wider community</p>		<p>gathering + supportive atmosphere + sharing)</p> <p>(Difference or change + wellbeing + on the carer's terms)</p>	

Appendix 9. Sponsorship Approval.

Dr Warren Donnellan
Institute of Psychology, Health
and Society



Dr Neil French
Head of Clinical Operations

Clinical Directorate
4th Floor Thompson Yates Building
Faculty of Health and Life Sciences
University of Liverpool
Liverpool L69 3GB

T: +44 (0)151 794 5852
Email: sponsor@liv.ac.uk

16 March 2021

Sponsor Ref: UoL001614

Re: Sponsorship Approval

“Exploring Resilience in Cohabiting Couples where One Person has a Diagnosis of Young-Onset Dementia - A Constructivist Grounded Theory Study”

Dear Dr Donnellan,

After consideration at the JRO Non Interventional Sponsorship Sub Committee on 20th January 2021 and review by the Chair I am pleased to confirm that the University of Liverpool is prepared to act as Sponsor under the UK Policy Framework for Health and Social Care Research (v3.2 10th October 2017) for the above study.

The following documents have been received by the Joint Research Office

Document title	Version	Date
Protocol	1	08/03/21

Please note this letter does NOT allow you to commence recruitment to your study.

A notification of Sponsor Permission to Proceed will be issued when governance and regulatory requirements have been met. Please see Appendix 1 to this letter for a list of the documents required.

If you have not already applied for regulatory approvals through IRAS you may now do so at <https://www.myresearchproject.org.uk/Home.aspx> (see SOP013).

In order to meet the requirements of the UK Policy Framework for Health and Social Care Research (v3.2 10th October 2017), the University requires you to agree to the following Chief Investigator responsibilities. Please see SOP006 for further details of delegated responsibilities;

TEM012 JRO UoL Sponsor Approval template
Version 7.02 Date 21/02/2018

Page 1 of 5

Appendix 10. HRA and NHS Ethical Approval.



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Dr Warren Donnellan
University of Liverpool
Eleanor Rathbone Building, Bedford Street South
Liverpool
L69 7ZA

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

16 July 2021

Dear Dr Donnellan

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Exploring Resilience in Cohabiting Couples where One Person has a Diagnosis of Young-Onset Dementia: A Constructivist Grounded Theory Study

IRAS project ID: 291619

Protocol number: UoL001614

REC reference: 21/NW/0179

Sponsor University of Liverpool

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 291619. Please quote this on all correspondence.

Yours sincerely,
Amber Ecclestone

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Dr Neil French*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [Recruitment poster]	1	01 April 2021
Costing template (commercial projects) [Budget Information]	3	05 February 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Confirmation of Insurance]	1	27 July 2021
Interview schedules or topic guides for participants [Interview schedule]	1	07 May 2021
IRAS Application Form [IRAS_Form_21052021]		21 May 2021
Letter from funder [UoL Research Review Committee approval]	1	15 September 2020
Letter from sponsor [Sponsor Approval]	1	16 March 2021
Letters of invitation to participant [Letter of Invitation]	1	25 June 2021
Other [Distress Protocol v1]	1	26 March 2021
Other [response to HRA assessment queries]		
Participant consent form [Consent Form v2]	2	25 June 2021
Participant information sheet (PIS) [Participant Information Sheet v2]	2	25 June 2021
Research protocol or project proposal [Protocol]	1	08 March 2021
Summary CV for Chief Investigator (CI) [CI CV]	1	30 April 2021
Summary CV for student [Student CV]	1	07 May 2021
Summary CV for supervisor (student research)		



Health Research Authority

North West - Greater Manchester East Research Ethics Committee

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

16 July 2021

Dr Warren Donnellan
University of Liverpool
Eleanor Rathbone Building, Bedford Street South
Liverpool
L69 7ZA

Dear Dr Donnellan

Study title: Exploring Resilience in Cohabiting Couples where One Person has a Diagnosis of Young-Onset Dementia: A Constructivist Grounded Theory Study
REC reference: 21/NW/0179
Protocol number: UoL001614
IRAS project ID: 291619

Thank you for your response of 02 July 2021, to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study

- Final report
- Reporting results

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [Recruitment poster]	1	01 April 2021
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Summary CV for Chief Investigator (CI) [CI CV]	1	30 April 2021
Summary CV for student [Student CV]	1	07 May 2021
Summary CV for supervisor (student research)		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

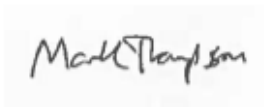
We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS project ID: 291619 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



On behalf of Dr Michael Hollingsworth
Vice Chair

Email: gmeast.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: Dr Neil French

Appendix 11. Reflexive statement.

My experiences, both personal and professional, have influenced the way in which I selected and approached this research topic. This reflexive statement aims to consider those factors, as well as the epistemological approach of the methodology.

Professionally, I was initially drawn to working with older people due to the influence of my grandparents. After suddenly and unexpectedly losing my grandfather to a heart attack, I became interested in the role of stress and coping on physical health which may have been my way of working through my grief. This led me to completing an MSc in Health Psychology to help me understand this further. It also allowed me the chance to move back home and be closer to family. During this time, I conducted research exploring when older adults would consider seeking the support of health care professionals for memory-related concerns. Whilst my grandfather did not have memory problems, he did not seek support from a health care professional until the months preceding his death. I wondered what prevented him from this.

I have held various paid employment posts prior to becoming a Trainee Clinical Psychologist working with people living with dementia. These roles varied from conducting neuropsychological assessments to supporting care home staff and residents alongside a multi-disciplinary team. Those presenting with dementia concerns under the age of 65 were seen by qualified practitioners due to the perceived complexity of the circumstances. Therefore, I had limited input with this age group, piquing my curiosity as to what was deemed complex in young onset dementia.

Through my work and research experiences, I gained an interest in considering the wider support systems around the person with dementia as they hold a pivotal role in supporting the ongoing wellbeing of their loved one. I began to recognise how the supporters or carers of a person needed to attend to themselves. I often heard the phrase “you can’t pour from an empty cup” and recognised how true this was when working with care home staff who had numerous demands placed upon their time. I wondered with staff and family members about where they drew their strength from when supporting a loved one with dementia. We built this into formulations and case discussions, making them more systemic.

My interest in the wellbeing of supporters, particularly family, was further developed when my mother was diagnosed with cancer. Whilst this disease was happening to her, it also affected those of us around her (i.e., me, my siblings, my mother’s partner). Whilst the cancer did not respond to chemotherapy, we were fortunate that surgery could remove it. When she was recovering in intensive care, a very clinical environment, she received care from a compassionate nurse who made sure to include us in the process. I remember feeling very grateful towards her as she seemed to understand the effect it was having on us as well as my mother. I was working as an Assistant Psychologist in an acute mental health inpatient setting at the time. Whilst my role was to support the mental health of patients, I was struck by how little the team also included the wellbeing of immediate family members or carers into this. I was curious about what the experience was also like for them, and how they were coping.

I did not have a detailed understanding of what resilience meant prior to approaching this research topic. Given the rhetoric around it, I had assumed resilience was an internal construct, so it was up to individuals to draw strength from within. I disliked this idea as it implied that if you were not resilient then it was somehow your fault. I was not aware of the literature around this topic until presented with the ecological resilience framework in which the empirical study is based upon. Resilience as a concept then began to make more sense; this was an accessible model which indicated various factors were required to support feeling resilient, not just from the individual but from their wider environments, including family.

When reviewing the literature around this, it became evident that the framework had only been applied to unpaid dementia carers. I found this interesting for an ecological model; carers have relationships with the person they care for, but this relationship was not overtly included in the methodology (i.e., interviewing dyads).

A constructivist grounded theory approach felt applicable to this approach for various reasons: I had already begun to develop my knowledge on the ecological resilience framework; I had professional experience of working with carers; I had personal experience of adversity; my supervisors had professional experience of research in this area, including dementia and carers; and the framework could be further developed by focusing on dyads where one person cared for their loved one. Grounded theory is a methodology which attempts to explore how people make sense of the world. In my opinion, this should also include the researcher's understanding, which is another reason to use the constructivist approach. How do I interpret what participants tell me?

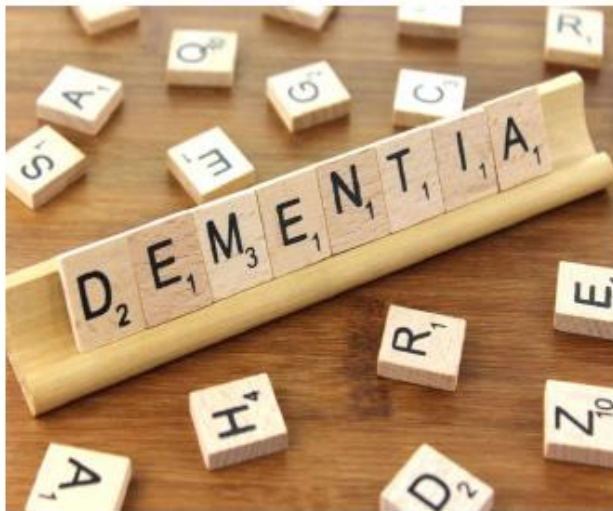
I already hold assumptions about what I might find in the data I gather. I will not assume partners refer to themselves as a carer. I believe the partner who provides a supporting or caring role will also have to take on more responsibility in other areas of their life as dementia symptoms develop. I wonder how this will impact on their perceived resiliency, and in turn how this will impact on the person with dementia's resilience. My focus on young onset dementia is interesting. I am curious about how dementia impacts on people at an earlier stage of their life than expected. My assumption is that they will be less able to hold employment, impacting on their financial stability and self-esteem as their role shifts and changes within their families. I also wonder about their journey to diagnosis. Were they reluctant to seek support? Did they expect a dementia diagnosis? Were they initially diagnosed with an alternative ailment? What was the testing process like and how did this affect them and their immediate relationships?

Given these are assumptions I already hold, I will need to keep these in mind when reviewing the data I gather as these questions could lead to an over-interpretation of responses. I will create memos, like a diary, after interviewing couples, and whilst I work through their data. In these I will note any pertinent thoughts, helping me to consider if my interpretation is biased towards an assumption I have. Research supervision will also have an important role in this. These memos will also help to answer the aims of the study.

Version2
27th August 2021



RESEARCH OPPORTUNITY



Have you or your partner
received a diagnosis of
Young-Onset Dementia?

Would you like to talk
about what life was like
before and after the
diagnosis?

NHS
Mersey Care
NHS Foundation Trust

NHS
Cheshire and
Wirral Partnership
NHS Foundation Trust

What would this involve?

We are looking to speak with **couples** who have been together for at least 3 years, where one person in the couple has **young-onset dementia**.

This will involve an **online interview** for up to 60 minutes with Louise Sheppard (Trainee Clinical Psychologist, University of Liverpool).

You will need access to a device (e.g. laptop or iPad) which has a camera and a microphone.

For more information, **please contact your health care professional**.

Appendix 13. Participant Information Sheet.

Version 3
27th August 2021
IRAS ID: 291619



Participant Information Sheet

Project Title: Exploring Resilience in Cohabiting Couples where One Person has a Diagnosis of Young-Onset Dementia - A Constructivist Grounded Theory Study

You are being invited to take part in a research project. Before deciding whether to do so, it is important to understand what is involved in the project and why. Please keep this information sheet as it will also explain what will happen once you have taken part, and how to contact the researcher.

You can discuss any of the following information with the researcher (contact details are included at the end of this sheet). As this study involves being interviewed with your partner, please discuss this information with them as both of you will need to provide your own consent to take part in this piece of research.

This research project is part of a course requirement for a Doctorate in Clinical Psychology with the University of Liverpool. The project is expected to come to an end in May 2022. Ethical approval has been granted by the North West – Greater Manchester East Research Ethics Committee (REC reference: 21/NW/0179).

What is being studied?

This study will explore what helps or hinders feeling resilient in couples who live together where one person in the couple has received a diagnosis of young-onset dementia. Questions will explore your thoughts around this, focusing initially on life before dementia.

Why have I been chosen?

Your health care provider (Merseycare NHS Foundation trust or Cheshire and Wirral Partnership NHS Trust) may have identified you as a potential participant and then provided you with this information. Alternatively, you may have seen a poster about this research project and want to know more.

You have been invited to consider taking part in this study because you live with your partner, and one of you has young-onset dementia (also referred to as early-onset dementia), diagnosed at least 6 months ago. You will have been in a relationship with your partner for at least 3 years.

In order to take part in this study, you will also need to have access to the internet. You will need to be able to use a device such as a laptop which has a webcam and a microphone, as interviews will take place via an online video platform called Zoom.

Do I have to take part?

No, taking part is completely voluntary and your decision. It will not affect the care you receive from your NHS team. This study involves talking to you as a couple, so it is important that both you and your partner want to take part.

Before taking part, you and your partner will be asked what you would like to happen to your data should your capacity to consent change during the time of conducting the interview and writing up the report (i.e. in the two months after being interviewed).

If you do take part, you can later request to withdraw your data from the project by contacting the researcher if you change your mind. However, there will be a point in time where this will no longer be possible (due to writing up the data and sharing the results), so please contact the researcher as soon as you decide to withdraw your information. Your data can no longer be withdrawn from the study after two months of providing it as it will have been transcribed, analysed, and used to consider the questions asked during the course of the study.

What will happen during the study?

Once you have read this information sheet, please again consider if you would like to take part. If you would, please inform the researcher using the contact information below. The researcher will then ask you for a date and time to contact you via Zoom. During this initial online meeting, the researcher will describe what is involved in the study (similar to this information sheet) and answer any questions you may have. They will also send you a consent form via email. This must be read prior to being interviewed. It is anticipated that this initial meeting will take no longer than 10 to 15 minutes.

At the end of the initial meeting, the researcher will ask you for a second appointment time in which to interview you. They will ask you for a time at least a week after the initial appointment so you and your partner both have time to consider your involvement and whether you have any questions. The researcher will email you with this new appointment time.

It is anticipated that the second appointment will last for up to an hour. This appointment will be audio recorded following gaining your consent so the researcher can write up what has been said. The interview will start by asking you some demographic information, such as your age. Following this, questions will explore your thoughts around living with a dementia and your relationship with your partner. You will both be encouraged to provide answers. The role of the researcher will be to listen and to ask follow-up questions to explore your thoughts further. You will be asked to have pens and notepaper or post-it notes available to you both during this interview. This is so you can write down a thought or an idea that comes to mind whilst another person is talking.

The content of the interview will be guided by you and your partner. If you or your partner become distressed during the interview, the researcher will ask if you would like to take a

break or stop altogether. The researcher will be able to spend time with you whilst you feel this way if you would like them to. The researcher will also be able to signpost you to your health care provider for follow up support, or to dementia-specific charities who offer telephone support.

At the end of the appointment, the researcher will ask if you would like to see a transcript of your interview once it has been written up.

Are there any risks or benefits to taking part?

If you should experience any discomfort or distress whilst being interviewed, please inform the researcher immediately. Whilst the questions are not intended to cause distress, you can abstain from answering any questions you may be uncomfortable with. If you become distressed, the researcher will pause the interview and provide time for you to consider whether to continue, or to withdraw your data from the study.

If you experience distress at any point, there are some organisations which can offer support via the phone, or they will have more information on their websites. These include:

- Dementia Support UK (0800 888 6678) - <https://www.dementiauk.org/get-support/diagnosis-and-next-steps/sources-of-support-and-advice/>
- Alzheimer's Society (0333 150 3456) - <https://www.alzheimers.org.uk/get-support>
- Your GP or Community Mental Health Team (if you are currently receiving support from one)
- Samaritans (116 123) - <https://www.samaritans.org/how-we-can-help/>

There are some indirect benefits to taking part in this study and sharing your experiences. As the project will be submitted for publication to an academic journal, you will have contributed to dementia research. This may help services such as the NHS when supporting people diagnosed with young-onset dementia and their family in the future.

Additionally, as a couple, you and your partner will be entered into a draw to win one of two £50 Amazon vouchers as a thank you for your contribution.

Will my involvement in the study be kept confidential?

The researcher will not have access to any of your NHS records. The researcher will only have your name and contact email address which you will have provided by emailing them to learn more about the study. This email account is only accessible by the researcher. The researcher will only email you to arrange the Zoom meetings, and to provide you with a copy of your transcript if you wish to have this. The researcher will also make contact between 6 and 12 months after your interview to share a summary of the study's findings,

but only if you wish to receive this. The only other reason the researcher may contact you is if you email them with a question, or to ask for your data to be withdrawn from the study.

It will not be possible to identify you in the write up of the study or any future publications. The researcher will ask both you and your partner to come up with a false name each. This enables the researcher to keep your data confidential whilst it is being written into a report as those who read it will not know who you are.

The interview appointment will be audio recorded onto a password protected device only accessible by the researcher. This is so that the interview can be transcribed afterwards for analysis. Audio files will be stored securely on the University of Liverpool's server.

Your interview will either be transcribed by the researcher, or by a reputable transcription company who will anonymise your data and link it to a pseudonym. If you would like more information about this company, please ask the researcher. Transcribers with this company will have signed a confidentiality agreement.

If you shared something during the interview which caused the researcher to feel concern for your wellbeing, or for the wellbeing of those around you, they will need to provide this information to your NHS care team if you are under the care of one (such as a Community Mental Health Team) in order to support you appropriately. Where possible, the researcher will inform you of this prior to breaking this confidentiality. Please discuss this with the researcher prior to taking part if you have any concerns or questions about this.

How will my data be used?

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules. Researchers must show that their research takes account of the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checks this before the research starts.

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

We will need to use information from you for this research project. This information will include:

- your name and email address – provided by you to the research team, also known to your NHS care team if this was how you were made aware of the study

People will use this information to do the research or to check your records to make sure that the research is being done properly. We will keep all information about you safe and secure. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The Supervisor acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Warren Donnellan (ps0u9265@liverpool.ac.uk).

Further information on how your data will be used can be found in the table below:

How will my data be collected?	Data collected during an interview will be audio recorded so it can be transcribed. This audio data will be collected via a University of Liverpool device which is password protected and only accessible by the researcher. Transcribed data will be anonymised and linked to a pseudonym.
How will my data be stored?	Electronically on the University of Liverpool's secure servers ('Active Data Storage'), managed by the Liverpool Research Data team.
How long will my data be stored for?	10 years
What measures are in place to protect the security and confidentiality of my data?	University of Liverpool devices are password protected, and data is stored on the University's secure servers.
Will my data be anonymised?	Yes, you will be asked to create a pseudonym which will be linked to the data you provide during the interview.
How will my data be used?	The researcher will use your email address to arrange online meetings or answer your questions. Data provided during an interview will be transcribed for analysis. It will be anonymised during this process and linked to a pseudonym. Demographic data (e.g. age) will also be collected during your interview. Anonymised data linked to the chosen pseudonym will be analysed and written up as part of a course requirement for the University of Liverpool's Doctorate in Clinical Psychology. This may also be published in an academic journal and/or presented at conferences.
Who will have access to my data?	The researcher named at the end of this information sheet will have access to your email address, name and audio data from your interview.

Will my data be archived for use in other research projects in the future?	Data may be used for future research projects.
How will my data be destroyed?	Destruction of the data will comply with the University of Liverpool's Information Security Policy.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team

What will happen to the results of this study?

The interview data from this study will be written up as part of a Doctorate in Clinical Psychology course requirement with the University of Liverpool. It is anticipated that a final version of this will be completed by May 2022. It is also hoped that following this it will be published in an academic journal and/or presented at conferences. Only anonymised quotes linked to a pseudonym will be used in publications.

Who is funding the project?

This study is sponsored by the University of Liverpool who are providing any funding requirements.

Who do I contact if I have a complaint?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr Warren Donnellan at ps0u9265@liverpool.ac.uk and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

Version 3
27th August 2021
IRAS ID: 291619

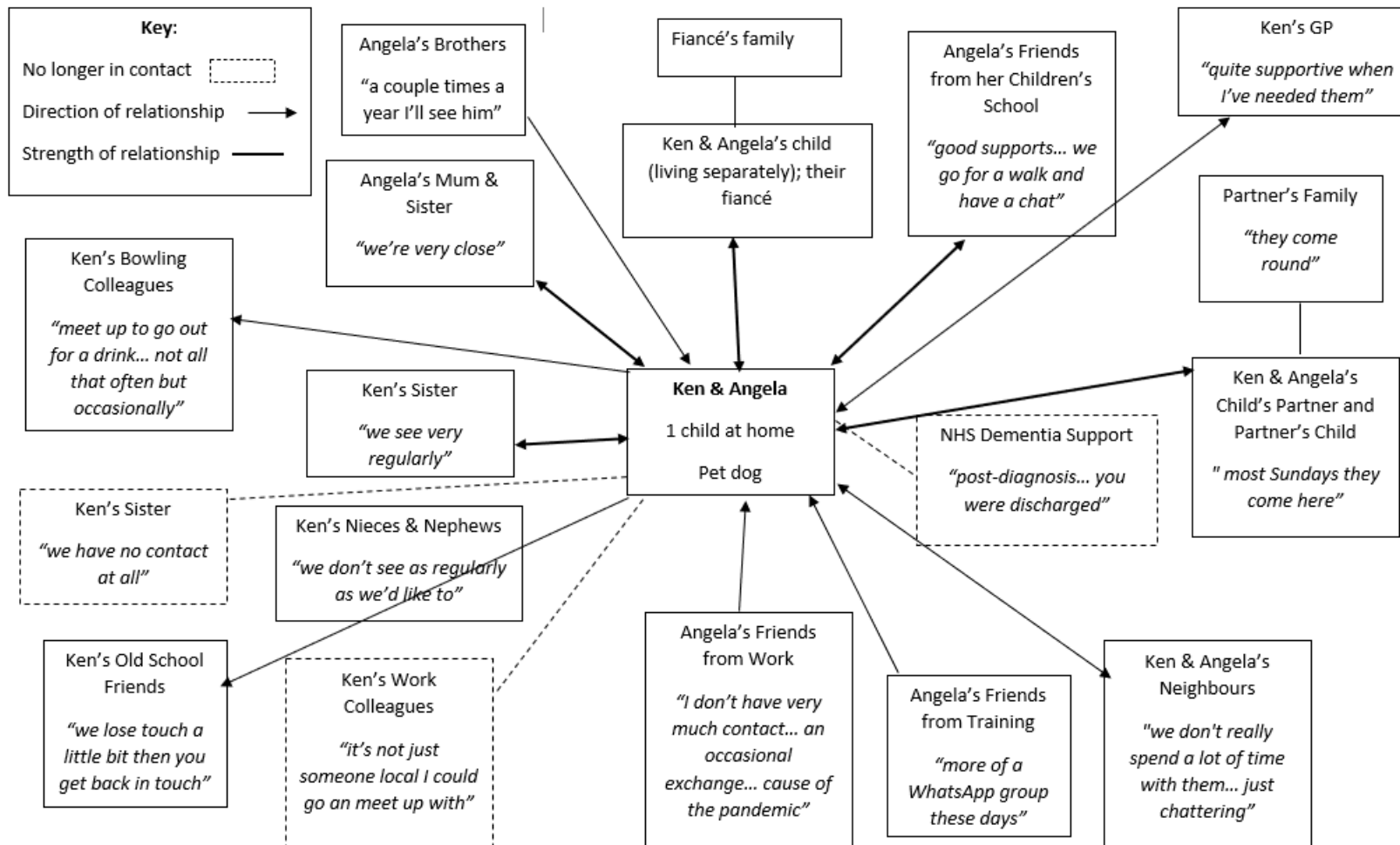


Contact Information

Lead researcher: Louise Sheppard (Trainee Clinical Psychologist, University of Liverpool) –
l.sheppard2@liverpool.ac.uk

Supervised by Dr Warren Donnellan and Dr Sarah Butchard (University of Liverpool)

Appendix 14. Ecomap Example.



Appendix 15. Interview Schedule.

Version 3 (version 2 updates from Dec 2021 in red, version 3 updates in blue 18/03/2022)
07/05/2021

Check they have a pen and paper to hand

Demographic questions:

1. When were you born (How old are you?)
2. Where were you born?
3. How long have you been together?
4. How long into your relationship were one of you diagnosed with dementia?
5. Do you currently work? If yes, what is your job role? If not, what was your employment?
6. If you no longer work, is this related to the dementia diagnosis or other factors?
7. **Ecomap: support structures ("Could we spend some time thinking about who is in your life and who supports you? Could we do this using a diagram to make it more visual?") – removed from here 17/12/2021**



Ecomapping.docx

Life **before** a dementia diagnosis:

1. Please describe how you would spend a typical day with your partner. (Prompt: what would you do together? Any hobbies? Trips?)
2. How would you describe your relationship then? (Prompt: do you have an example or a story that shows what your relationship was like before dementia came into your life? Did you have fun? Would you often have disagreements?)
3. Describe a time when you had to cope with a difficulty (prior to the diagnosis of dementia). (Prompt: when you had to overcome a challenge in your relationship)
4. Who or what would you turn to for support? (Prompt: Who would you have talked to during a difficult time?)
5. What personal characteristics have helped you? (Prompt: hobbies, sense of humour...)
6. What did you notice around the time of the dementia diagnosis? What did you do?
7. **Introduce Ecomap: support structures ("Could we spend some time thinking about who is in your life and who supports you? Could we do this using a diagram to make it more visual?")**
Now that we've thought about life prior to dementia, is anything or anyone missing?

After a dementia diagnosis:

1. What was it like to receive a diagnosis? What was your reaction? Where did you get information about it? Was it a quick/slow process?
2. What changed for you both afterwards? How did you respond to these changes? (Prompt: what has been the biggest change for you? For example, has your routine changed?)

3. Please describe how you would spend a typical day with your partner. (Prompt: have your roles and responsibilities changed following a diagnosis? Prior to covid.)
4. Has there been an impact on how you feel (your mood) following the changes in your life? If yes, what, if anything, helps here?
5. What is your relationship like now? (Prompt: do you have a story or an example? Increase in disagreements? Change in routine?)
6. Have the kinds of support you received changed at all? (Prompt: post-diagnostic groups for example – experience of these; Which people or places have been helpful to you?)
7. What personal characteristics have helped you? (Prompt: hobbies, sense of humour...)
8. Describe a time when you had to cope with a difficulty. How did you cope with this? (Prompt: consider experience of past events on how to cope with present difficulties).
9. What has it been like to live through the covid-19 pandemic whilst living with a dementia? (Prompt: any examples of difficulties? Adaptations? Positives to come out of it?) Or what effect has dementia had on coping with/living through the pandemic?
10. Have you noticed yourself considering or making plans for the future? Who or what is involved in these plans? If you do make plans, why? How does it help to consider the future?
11. Let's return to our diagram from earlier (Ecomap). Now that we've thought about life after being diagnosed with a dementia, is anything or anyone missing?

Is there anything you would like to talk about that we have not addressed so far? Have I missed anything?

Appendix 16. Example of Emerging Narrative – Appendix Edited to Ensure Participant Anonymity.

Reflections After Interview One (19/11/2021):

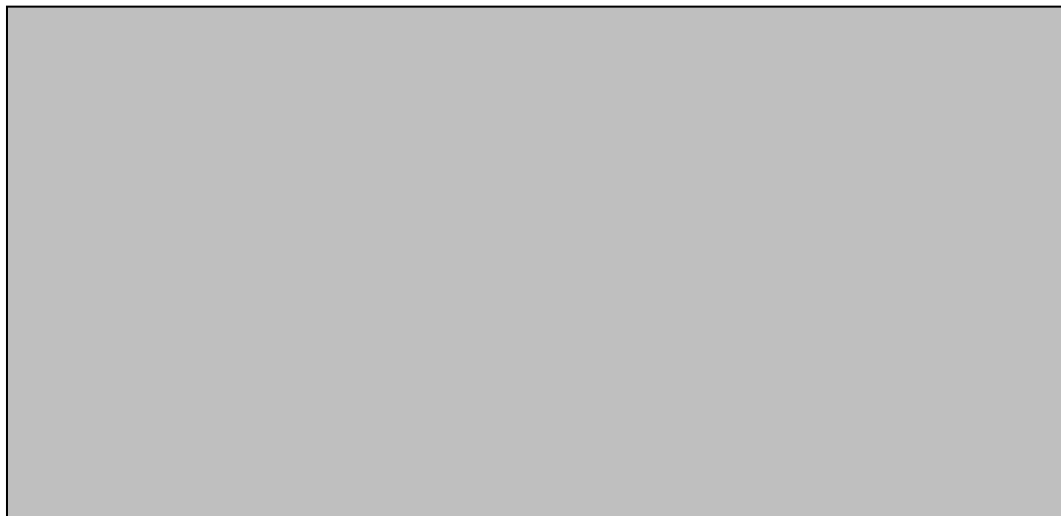
I was excited but also a little nervous to meet with the first couple this afternoon. Excited because I was finally getting the opportunity to speak with people, but nervous because it's been a while since interviewing for research. What if I got something wrong? Or forgot something?

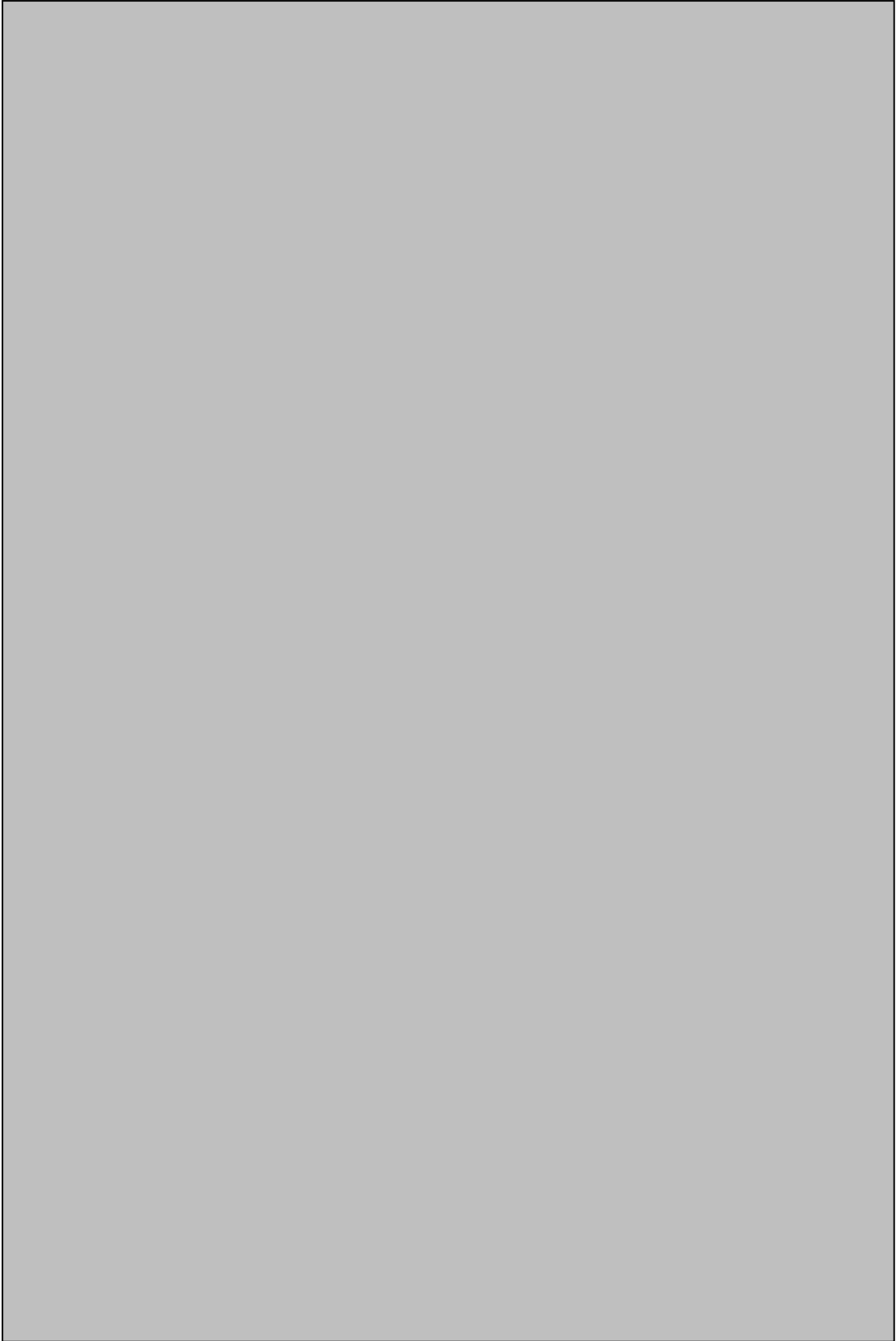
The couple put me at ease almost immediately. Funny how I thought it would have been the other way around. But from hearing them talk about their experiences, they were clearly so passionate to be involved in promoting awareness of younger people living with a dementia. They'd turned something so shocking (the diagnosis) into something that gave their life meaning and purpose, pulling them out of depression. Their sense of humour came through most clearly when sharing their thoughts on more difficult subjects such as the process of receiving a diagnosis. It was infectious. I couldn't help but smile or share in their laughter at times.

Their comments highlighted the importance of lived experience and peer support for those living with a dementia. This appeared to be a huge part of their lives, reflected in the amount of time they spent talking about this. They valued this more than input from health care professionals. Whilst this wasn't a shock to hear, it perhaps did feel a little odd as I am a mental health care professional, however in this context I am a researcher interviewing them.

During this interview I would often notice each person in the couple looking over to the other one, inviting them to speak or offer an opinion. I wonder how much of this would have been lost if we were not speaking via zoom but over the phone instead, or if I were interviewing them separately. This reinforces the idea for me that interviewing couples together was an important choice.

This first interview really highlighted a key learning point: it's been a while since I last conducted interviews for research. I realised halfway through the interview that I was being quite rigid in sticking with the questions on the interview schedule. I wonder what else might have been shared if I had been less strict with what questions I asked. I think by the end of the interview I felt more able to ask a question or two that wasn't on the schedule, and this led to participants sharing really interesting opinions on resilience, such as having a positive mental attitude, even though it wasn't referred to as resilience by myself or them.





Thoughts and Hypotheses Considered During Initial Coding:

A number of losses have been experienced by John, not just his friends, but also the coping mechanisms which came from being friends with them, such as drinking alcohol and “putting the world to rights”. John has also “surrendered” his driving license, a reminder of the importance of his job role which he has also lost due to the effects of the Alzheimer’s. Losses have been forced upon John following the dementia diagnosis. This also affects Vicky through loss of income (going down to one wage) and an increased awareness of the impact of changes on John’s mood. Is there a power imbalance? I.e., dementia vs John/the couple? Is dementia winning? Is John fighting back through creating the dementia support group? If this is the most applicable metaphor, perhaps John is winning as he has created purpose despite the losses forced upon him.

When it comes to the support group, partners split up and discuss their experiences separately, highlighting that having dementia and caring for a person with dementia are unique experiences. Is it a private experience that can only be understood by others in a similar position? Is it difficult for one group to understand the other? Or are there certain things that should remain unknown? Parts of the dementia experience are shielded or masked from the other person – this seems to serve a protective function, I.e., to minimise distress and protect the relationship. Peer support isn’t just for the person with dementia. This fits with Vicky’s comment towards the end of the interview where she emphasised that even though John has the diagnosis, they both live with it. “Different characters, not everybody gels” highlights that there is strength in coming together despite personal differences. There is something to be gained from receiving support or providing support to others.

The separation of person with dementia and partner during support groups mirrors the effect the diagnosis has had on the individual: “John struggled... more so than me” - dementia hits differently, it is a struggle to adjust, so how do you start to? Is acknowledging the struggle the start of adapting to the diagnosis? I.e., figuring out what it means for you and those around you, considering what kind of impact it will have on you and your life/world view.

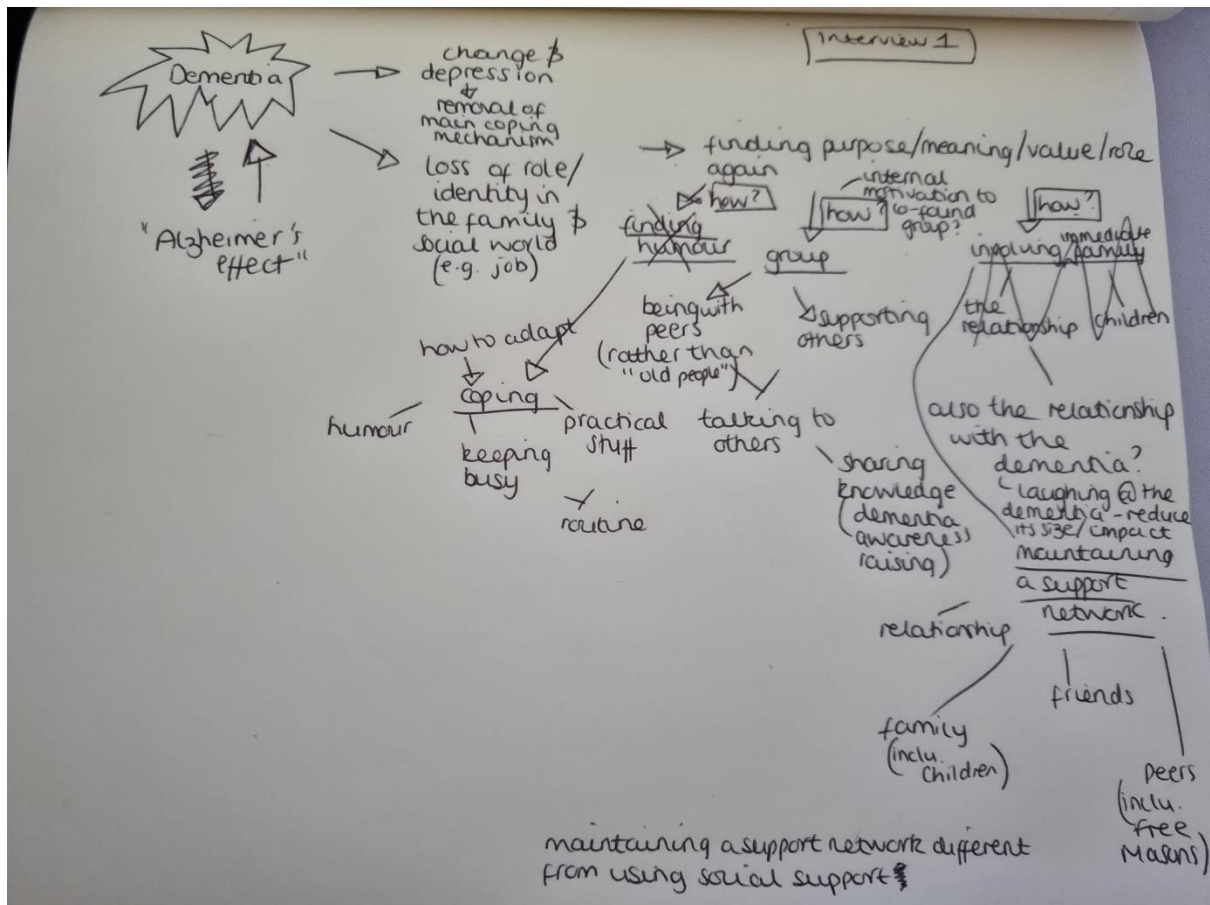
The emphasis on peer support rather than professional support would fit with the idea that the experience can only be understood by those in their shoes. Professionals can hold certain knowledge, but this isn’t hands on experience, or it isn’t enough for the couple. Even so, the couple view their professional support positively, as something which they are lucky to receive and have ongoing access to. This is said with the awareness that it is location-specific, not everyone would be able to receive it due to geography and local services on offer to support people. They think of their

post-diagnostic nurse very highly, perhaps indicating the strength of the relationship. They are easily contactable and can offer different types of support, e.g., practical, or emotional. From talking to Vicky, she values practical advice and having tasks she can complete to feel she is achieving something which will ultimately be helpful to the situation.



Stimulation is viewed as your own responsibility, however covid tested this. For John, there may have been a reliance on someone to initiate a task or keep them company. Not clear is this was due to his confidence or a change in abilities – though John did refer to a change in his emotions throughout the lockdowns, e.g., less empathic.

Vicky copes with changes by spending time outside of the immediate family. Is this a way of escaping or avoiding reminders of dementia? Keeping busy is a tool employed to cope, e.g., through distraction or avoidance of difficult feelings.



Appendix 17. Full List of Codes.

A blow	Care plan
Acceptance	Change
Accountability	Cheesy
Adapting	Children
Alone or Excluded	Circle of friends
Alright	Clique
Alzheimer's effect	Close
Amenities	Close friends
Anger	Coming out
Another death	Community
Anxiety	Community follow-up
Anything is possible	Company
Appropriate support	Comparison
Attitude	Compartmentalise
Awareness raising	Confusing
Bad luck	Considerate
Bad thing	Control
Balance	Coping
Ball rolling	COVID
Before diagnosis	Creating support
Being active	Creeping in
Being tested	Criticism
Big hit	Cuddling
Big thing	Cure
Bottling up	Dancing
Bowling	Day by day
Brain training	Decision making
Bright side	Dedication
Busy	Dementia awareness
Can't be bothered	Dementia friends
Capacity	Dementia-friendly environment

Denial
Depressed
Diagnosis
Diagnostic process
Difficult
Disagreements
Disappeared
Doctors
Doing more
Dole
Doom and gloom
Downtime
Drain on resources
Drifted apart
Drinking
Driving
Dynamics
Early phase
Embarrassed
Emergency contact
Emotions
Encouraged to contact
Environment
Errands
Escape
Expected
Experience of dementia
Experiences of caring
Family contact
Family life
Family resource
Feeling bad
Fighting for help
Finances
Finite resource
Fish out of water
Fit
Fix this
Fixing or dealing with
Followed advice
Food parcels
Form filling
Founders
Freebies
Fretting
Friends
Frustration
Fundraising
Future care needs
Future dreams
[Future plans](#)
Get things done
Getting involved
Getting lost
Getting older
Getting on
Getting through it
Giving back
Giving in
Giving up
Going out
Golf

Good and bad days	Journey
Good person	Keep to self
Got a place	Keeping active
Government or Legal Systems	Knowing
Gradual thing	Lack of control
Grumpy	Laid back
Guidance	Laughter
Gut-wrenching	Law
Happy	Learned to cope
Hard work	Learning
Health and safety	Learning about dementia
Hobbies	Learning curve
Holidays	Legal things
Honesty	Leisure time
Hope	Less independence
House	Letting go
Humour	Lies
If only	Little things
Ill-health	Live life
Impact	Living with pain
Important things	Loner
in our shoes	Look after
Inappropriate humour	Loss
Inclusion	Love of driving
Income change	Luck
Independence	Make jokes
Influencing policy	Making memories
Information gathering	Making sense
Introducing others	Making the most of
Isolating	Managing
Join in	Mellowed

Memory loss	Out of context
Mentality	Outlook
Moody	Own company
Most couples	Pandemic
Moving on	Party
My job	Patience
My time	Peace
Nagging	Peers
Need a break	Pension
Needing help	Pensions and wills
Neighbours	Permission
Nerves	Perspective
New roles	Pets
No help	Physical health
No one	PIP
No reprieve	Plan for the now
Normal	Plan for the worst
Not alone	Practicalities
Not for me	Pre-diagnosis
Not knowing	Preparation
Not the same	Priorities
Nothing for YOD	Problem solving
Nothing wrong	Processes
Noticing change	Professional support
Obstacles	Professor
Old age	Prognosis
Old people	Pub
On hold	Pull together
Organisation	Put up with
Other people	Questioned diagnosis
Out of character	Quiet time

Rationalise
Reach out
Reaching out
Refusal
Relaxing
Relief
Repetition
Repetitive life
Research
Resentment
Rest
Retiring
Right to choose
Roles
Routine
Sad
Sad things
Safe place
Same page
Scared
School
School contacts
Secrets
Seeking help
Selfless
Shared interest
Sharing
Sharing knowledge
Shock
Short- sighted
Side-tracked
Signing over
Similarities
Sleep
Sleeplessness
Snapping back
Sneak up
Social
Social butterfly
Social services
Something wrong
Soul mates
Space away
Specialist nurse
Spending
Spending time
Spoiling Christmas
Staying Involved
Stiff upper lip
Stigma
Still him
Stoic
Stopped driving
Stopped going out
Stories
Stress
Strong people
Strong woman
Struggle
Struggling
Stuck
Stupid things

Suicide
Support group
Support network
Supporting partner
Supports
Surrender or Sacrifice
Swearing
Symptoms
Taking Charge
Talking
Task-orientated
Technology
Terrible time
Thankful
That's life
The beginnings
The relationship
The same
Their needs
Therapeutic
Think before doing
Thinking
Thriving
Time
Time apart
Time to think
Together
Together but alone
Trauma
Travelling
Trust
Understanding
United front
Unsupportive systems
Useless
Walk away
Way I am
Weekend
Whole group
Wish for death
Won't remember
Work
Work hard
Workmates
Worry
Worthwhile

Appendix 18. Example of Code Condensing.

08/05/2022

Interview 3

Factors which help/hider/moderate at each level

Individual:



Facilitates	Hinders	Moderates (or in moderation/need to balance)
<ul style="list-style-type: none"> • Laughter + humour • Travelling + safe place • Being active • Fit • Adapting (interacts with work/retirement at societal level) • Acceptance + making the most of + stiff upper lip + getting through it + freebies + bad thing • Laid back • Relaxing • Giving back • Comparison • Awareness raising • Surrender • Repetition + organisation 	<ul style="list-style-type: none"> • Ill-health + prognosis + sleep + memory loss + dementia • awareness + difficult • Finances • Anxiety + worry + stupid things + out of character + sleeplessness • Frustration + obstacles • Denial + giving in • Stress • Sad • Struggling • Shock • Old age 	<ul style="list-style-type: none"> • Time (interaction with work/retirement at societal level) • Think before doing + permission • Technology + creeping in • Learning about dementia (interacts with societal level <u>i.e.</u> where the info comes from) + information gathering • Hobbies (facilitates until the person cannot do it anymore) + dancing • Independence (has changed over time) + getting lost + driving + big thing

		<ul style="list-style-type: none"> • <u>Future plans</u> + on hold + future dreams • Side-tracked
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What doesn't fit: attitude (would go under facilitates but little info)

Community:

Facilitates	Hinders	Moderates (or in moderation/need to balance)
<ul style="list-style-type: none"> • Together + the relationship + supporting partner (interacts with adapting, <u>e.g.</u> still cooks but partner is there too) + united front + weekend + staying involved + same page + cheesy • Friends + talking • Family contact + family resource + routine • Social 	<ul style="list-style-type: none"> • Criticism + not knowing + nagging + disagreements 	<ul style="list-style-type: none"> • Children (hinders when they aren't close by) • Roles (change over time, partner wanting to adapt but PWD not ready to) • Creating support (not much for YOD, you <u>have to</u> go find it if you want it) + peers

<ul style="list-style-type: none"> • Close friends • Support group • Experience of dementia 		
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What doesn't fit: social butterfly – incorrectly coded (should be social); ball rolling

Societal:

Facilitates	Hinders	Moderates (or in moderation/need to balance)
<ul style="list-style-type: none"> • Retiring + pension (interacts with finances at individual level) 	<ul style="list-style-type: none"> • Nothing for YOD • Drain on resources • Stigma 	<ul style="list-style-type: none"> • Work (work-life balance, if you like your job, how work supports you) • Doctors + being tested + questioned diagnosis • diagnostic process + supports + secrets + making sense + learning curve + important things + guidance + trauma + spoiling Christmas • Legal things (need to apply at the right time) + followed advice + government or legal systems + form filing + dole