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'I have never bounced back': resilience and living with dementia

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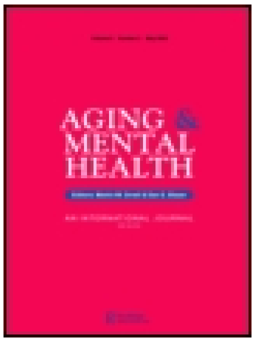

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'I have never bounced back': resilience and living with dementia

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ABSTRACT

Objective: This work responds to the limited research about resilience when living with dementia and develops a conceptual model to inform service development and healthcare practices for this population.

Methods: An iterative process of theory building across four phases of activity (scoping review $n=9$ studies), stakeholder engagement ($n=7$), interviews ($n=11$) generated a combined sample of 87 people living with dementia and their carers, including those affected by rare dementias to explore their lived experiences. An existing framework of resilience developed in other populations served as the starting point to analyse and synthesise the findings, inspiring a new conceptual model of resilience unique to the experience of living with dementia.

Results: The synthesis suggests resilience encompasses the daily struggles of living with a dementia; people are not flourishing, thriving or 'bouncing back', but are managing and adapting under pressure and stress. The conceptual model suggests resilience may be achieved through the collective and collaborative role of psychological strengths, practical approaches to adapting to life with dementia, continuing with hobbies, interests and activities, strong relationships with family and friends, peer support and education, participating in community activities and support from healthcare professionals. Most of these themes are not reflected in resilience outcome measures.

Conclusions: Practitioners adopting a strengths-based approach utilising the conceptual model at the point of diagnosis and post-diagnosis support may help individuals achieve resilience through appropriately tailored services and support. This 'resilience practice' could also extend to other degenerative or debilitating chronic conditions a person faces in their life course.

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Resilience; dementia; carers; qualitative

Introduction

Alzheimer's Disease International (Prince et al., 2015) estimates a new case of dementia develops every 3.2 s around the world. Given the limited medical treatments currently available and the absence of a cure, supporting people with dementia to live as well as they possibly can is an international (WHO, 2017a) policy priority.

Living as well as possible when faced with major difficulties is central to the concept of resilience (e.g. Windle, 2011). Some researchers suggest resilience is an individual attribute (e.g. Stoner et al., 2017) and a domain of positive psychology, the study of positive emotions that enable individuals to flourish and thrive (Seligman et al., 2005). Other researchers argue that people are not invulnerable, flourishing or meeting criteria for successful ageing, but can effectively negotiate, manage and adapt to significant sources of stress or trauma, and 'bounce back' in the face of adversity (Windle, 2011). Resilience is considered one of the factors influencing the social health of people living with dementia (Dröes et al., 2017) and is reflected in the changing narrative around dementia, with researchers now exploring the assets and strengths of people living with dementia that can help mitigate against poor outcomes (Clarke & Wolverson, 2016) and 'live well' despite the challenges of their dementia (Lamont et al., 2020). Building resilience is at the core of the WHO European policy framework for health and wellbeing and the United Nations Sustainable Development Goals (WHO, 2017b).

Despite this shift towards trying to understand how resilience and consequent favourable outcomes can be achieved, very little research has examined the resilience of people living with dementia (Conway et al., 2020; Windle et al., 2021). Moreover, a recent report on clinical practice indicates that promoting resilience is not embedded in everyday practice (Gauthier et al., 2021, p.188) even though this could inspire hope for the person being diagnosed that they could still 'do okay' despite their dementia.

Building knowledge and understanding about resilience in people living with dementia first requires a theory to enable 'the construction of explicit explanations in accounting for empirical findings' (Bengtson et al., 1999, p.5). But Conway et al. (2020) note there are few theoretical frameworks to understand resilience in people with dementia. The absence of a theoretical framework then leads to operational challenges regarding how resilience may

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be measured as an outcome and consequently, how it may be enhanced by health care services. There are currently no outcome measures developed with, and for people living with dementia (Stoner et al., 2017; Windle et al., 2022). All the resilience measures identified in the review of Windle et al. (2022) required further psychometric evaluation in both people living with dementia and their carers, and the conceptual adequacy of the measures as applied in these new populations was questionable.

Elsewhere, an ecological resilience framework informed by the review of Windle (2011) was formulated to understand resilience across the lifecourse, recognising that despite major difficulties, individuals continue to function and 'do okay' (Windle, 2012; Windle & Bennett, 2011). Inspired by Ecological Systems Theory (Bronfenbrenner, 1994) this framework identifies three non-hierarchical, interacting levels (individual, community and society) reflecting intraindividual, interpersonal and socioenvironmental factors, described as the 'resilience reserve' by Christie (2020, p.47) that can offset the effects of major difficulties. This theoretical framework shares conceptual overlap with the WHO (2017b) European policy framework, which notes resilience can be strengthened at three levels: individual, community and system/society.

The ecological resilience framework is not specific to the experience of dementia but in the absence of one that is, it has been used as an initial foundation to further understand and advance knowledge of the resilience of family carers of people living with dementia (Cherry et al., 2013; Donnellan et al., 2017; Han et al., 2019; Joling et al., 2016; Teahan et al., 2018) and how interventions could foster resilience in people living with dementia (Whelan et al., 2020). One study sought to interpret the resilience of people living with dementia in residential care homes using the framework, although the study was not designed to explore resilience specifically (Newman et al., 2018).

Aims of this research

This work responds to the limited research about the experience of resilience for the person living with dementia. It seeks to develop a conceptual model for this population to inform service development and health and care practices. Our investigation explores how (if at all), can we be resilient when facing a life-changing, degenerative condition, namely dementia?

Methods

Four iterative phases of primary and secondary research explored lived experiences (Figure 1). It used the ecological framework of resilience (Windle, 2011) as a starting point for organising the findings of the phases and shape the development of a new conceptual model tailored to the unique experiences of living with dementia. Given the limited research in the area we wanted to draw on different experiences and represent the voices of the individuals, and first started with a scoping review, reading, reflecting and generating an initial theory of how people living with dementia experience resilience. Building on this initial case of secondary data, we sought further insights from individuals living with dementia to augment, refute or corroborate the initial findings, using two different methods (stakeholder engagement and individual interviews) with different sources of participants with the aim of representing a diverse sample. All three phases of work were then synthesised to generate a conceptual model of the key features of resilience in people living with dementia.

Researcher characteristics

The research team came from a variety of disciplinary backgrounds and efforts were made to reduce researcher bias. The main analysis in Phase 1 and interviews in Phases 2 and 3 were undertaken by JR, new to the area of resilience. The analysis in Phase 3 was conducted by three authors (KAS, CM and JR). KAS and CM were independent of the interview schedule development and data collection and had no prior expertise of the area of resilience in dementia. GW has expertise in resilience and contributed to all phases of the analysis. Others (MPS, JS, EB and CHJ) had considerable expertise in dementia but not resilience and were able to provide comprehensive and critical reflections on the interpretation of the findings.

Phase 1 - scoping review

A scoping review is an exploratory methodology for charting concepts and is useful when a subject area has not been extensively explored, enabling a broad range of literature to be captured, regardless of the study design (Arksey & O'Malley, 2005). Study quality is not assessed. Instead, a conceptual overview is provided, and gaps identified, guided by the question: 'what is known from the existing literature about how people living with dementia experience resilience?' The PRISMA-ScR checklist was followed to ensure clarity of reporting (Tricco et al., 2018).

Study identification

Systematic principles of searching and screening identified published research. A comprehensive search of the literature was conducted from inception to 25/04/2020 by the author JR and updated 05/07/2021. The following databases were searched: ASSIA ProQuest, PsycInfo, CINAHL Plus and PubMed. Search terms, restricted to titles and abstracts, were dementia OR Alzheimer* OR primary progressive aphasia OR posterior

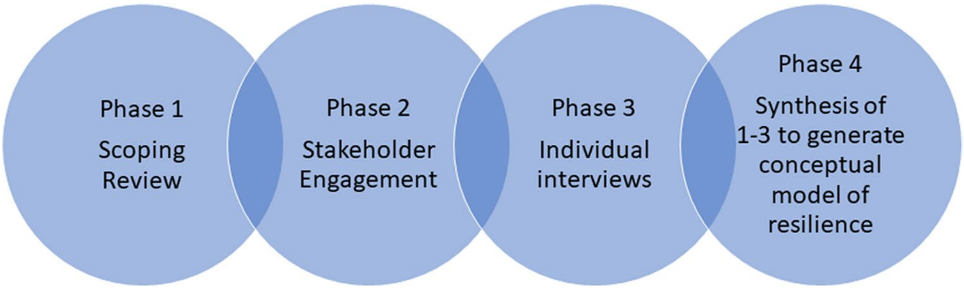

Figure 1. The stages of activity across the research.

cortical atrophy AND resilien*. Full searches in Supplementary File 1. The initial search was supplemented by hand-searching the reference list of included articles.

Screening

Eligibility criteria. Peer-reviewed primary research was included if: a main study focus was on resilience; participants were people living with any type of dementia; and the study described resilience from the participants' perspective. If the study also reflected the voice of the carer (or others), we extracted only data referring to the resilience of the person with dementia. If this was not possible, the study was excluded. Studies were excluded if they were not published in English, not human participants, biology/genetic/cellular focussed research, drug/chemical studies, or about prevalence/risk factors for dementia/symptoms/diagnosis or were intervention studies.

Study selection

The search results were saved into RefWorks. Titles and abstracts were screened by JR and a random sample of 10% independently reviewed for consistency by CHJ, with a 95% accuracy in inclusion/exclusion decisions. Discrepancies were discussed until both reviewers agreed on a decision. Full-text screening was carried out by JR. The preliminary final list of full text articles were reviewed for inclusion independently by GW. The PRISMA flow diagram (Figure 2) illustrates the review process.

Data charting process

A Microsoft Excel spreadsheet was developed and the following data extracted: publication information (authors, year, and country); design (objectives, methodological approach, participants, information about the interview process); conceptualisations or definitions of resilience used and the study findings

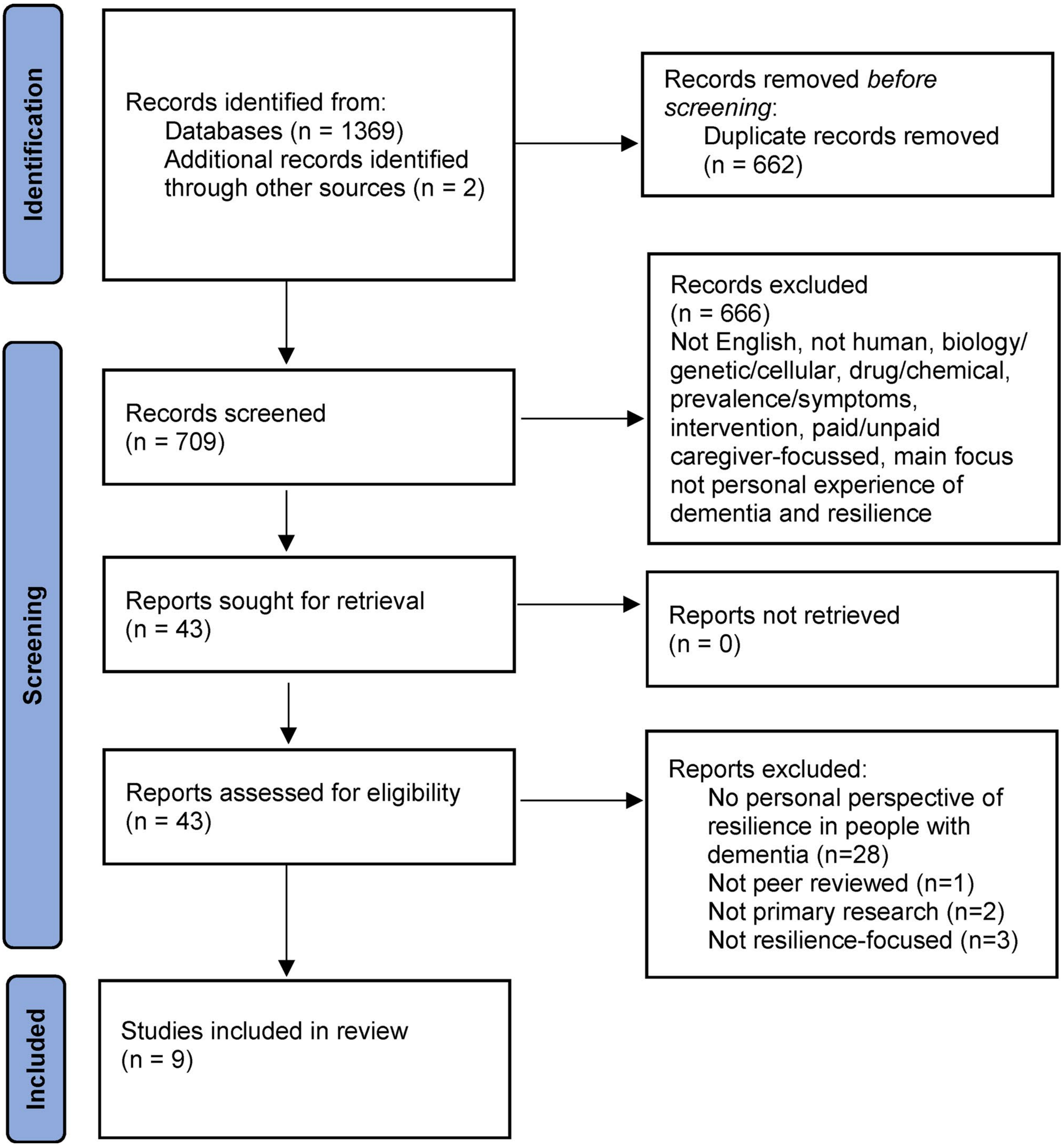

Figure 2. PRISMA flow diagram of the review process.

relating to the personal experiences of resilience. Reviewers JR and CHJ independently extracted data for all studies. These were then compared with any discrepancies regarding extraction being discussed before making a final decision.

Analysis

A thematic analysis (Braun & Clarke, 2006) explored the findings of the included studies to understand resilience from the perspective of people living with dementia and identify factors important for resilience. This consisted of a hybrid approach, whereby key themes were initially derived by JR via detailed reading, followed by inductive coding. This was an iterative process with refinements on coding and themes reached through ongoing discussion with CHJ and GW. Themes were then organised into the individual, community, and societal levels of the ecological framework of resilience.

Phase 2 – exploring resilience with people living with dementia and their carers: Stakeholder engagement activity

Data collection

Five people living with dementia and two carers who are members of the 'Caban group' and work with the university as Dementia Educators agreed to contribute to this phase of the study as part of their role as educators, and provide their opinions on the topic of resilience and help shape subsequent research questions. Informed by the findings of Phase 1, questions were developed ahead of the day to help guide the discussion, such as, 'When you hear the word resilience, what does it mean to you?', 'What are your sources of strength? What helps you manage?' and 'Resilience has been described in the past as 'bouncing back' in the face of life's challenges. What do you think of this definition in relation to living with dementia?' A two-hour meeting was held in a university meeting room in July 2019 and facilitated by two authors (JR and GW). The meeting was audio recorded, transcribed, and thematically analysed, with themes organised into the three levels of the ecological framework of resilience (as per the method described in Phase 1). The main themes from the discussion were presented back to the group in a subsequent meeting and the group agreed this represented their previously expressed opinions.

Phase 3- Exploring the resilience of people living with rare forms of dementia

Sampling and recruitment

Participants were recruited through the Rare Dementia Support (RDS) network as part of a programme approved by the UCL research ethics committee (8545/004: Rare Dementia Support Impact Study Brotherhood et al., 2020). An email was sent out by author EB to 95 potential participants (RDS members living in Wales and the NW England area), inviting people to discuss resilience in an online 1:1 interview, with a recruitment target of $N = 10$. Participants were required to be over 18 years old and have the capacity to understand, retain, weigh up and communicate the information required to make the decision to participate in the study. Proxy interviews with carers were conducted where the person with dementia was unable to take part in the interview (e.g. due to ill-health or capacity). Ten interviews were conducted (with 11 participants) representing one joint interview with a dyad ($n = 2$), $n = 2$ interviews with people with dementia and proxy interviews with carers ($n = 7$).

Including carer perceptions allowed the researchers to capture the trajectory of resilience as the disease progressed into later stages.

Data collection

Informed by the results of phases 1 and 2, a topic guide was developed by JR and GW to explore subjects such as perceptions of resilience and what helps them manage and 'do okay' (including prompts around sources of strength, informal and formal supports, social life, interests and attitudes). Semi-structured interviews using this topic guide were conducted by JR in May 2020, via the online platform GoToMeeting, and were digitally recorded then professionally transcribed. Data was stored in the UCL Data Safe Haven, a secure virtual platform.

Analysis

All analysis was conducted using NVivo (version 12) via secure remote access. Initial analysis was conducted by KAS and CM who were independent of the interview schedule development and data collection, facilitating a data driven approach to the initial analysis, unencumbered by prior expectations developed during phases 1 and 2. KAS and CM open coded separately the same interview given by a person with a rare dementia and then compared and contrasted codes to develop an initial coding framework. This initial framework was then applied to a second interview given by a carer, which was again coded separately, with codes compared for consistency. The framework was further adapted to reflect themes from a carer's perspective (for example, codes reflecting experiences of people with more advanced dementia, for instance experiences in care homes and end of life care). These initial two interviews were then recoded by KAS using this refined coding framework. The remaining eight interviews were split equally between KAS and CM for coding with frequent discussion about the interviews, codes and identified themes throughout the analysis process, with updates added to the coding framework. JR and CM then analysed the codes further to generate subthemes pertinent to the objective of the study, to inform the developing conceptual model. Subthemes were derived by reading and rereading the overarching codes 'managing and coping', 'support' and 'Resilience: definition/thoughts on' and identifying themes emerging from the interviews. These were discussed, adapted and agreed through discussions between JR and CM. Themes were then organised within the three levels of the ecological framework of resilience.

Phase 4 - Synthesis of phases 1-3 to generate a conceptual model of the key features of resilience in people living with dementia

To understand how people with dementia experience resilience, we utilised principles of grounded theory (Charmaz, 2014) and an iterative cycle of inductive, deductive, and abductive analysis and reflection throughout phases 1-3 supported a comprehensive synthesis of all data. The findings from each phase were mapped on to the results of previous phases, identifying where themes overlapped and where they differed. Where themes, sub-themes, and their contents overlapped these were merged into single themes. Where new themes were identified, data from previous phases was revisited to see if there was evidence of this new theme in earlier phases of work to ensure comprehensive coverage. This amalgamated data from across the three phases was used to generate a conceptual model of the key features of resilience in people living with dementia in Phase 4.

Results

Phase 1 scoping review

Database searches yielded 707 results after removal of duplicates. Titles and abstracts were screened using the eligibility criteria, leading to 43 results to review at full-text. Thirty-four articles were subsequently excluded because they either did not describe the personal perspective of resilience in people with dementia ($n = 28$), were not resilience-focussed ($n = 3$), were not peer-reviewed ($n = 1$)or were not primary research ($n = 2$). Nine articles were included in the review (See Figure 2).

Table 1 provides an overview of the study characteristics. These were from the United States ($n = 3$), Canada ($n = 1$), Ireland ($n = 1$) and the United Kingdom ($n = 4$). Six studies focussed primarily on people living with dementia, and three included carers or family members (data pertaining to the resilience of carers or family members were not extracted). Where ethnicity was reported, most of the participants were described as white. All studies employed qualitative methodology, sample sizes range from 2 to 13 (PLWD total $N = 69$; $M = 7.67$; S.$D = 3.71$), with most participants being in the early stages of their dementia. Four studies disclosed specific diagnoses of dementia of participants (Buggins et al., 2021; Conway et al., 2020; Harris, 2008; Pipon-Young et al., 2012), the most frequently reported being Alzheimer's Disease. Analysis of extracted data revealed 7 themes and 24 sub-themes that were organised within the three levels of the ecological resilience framework (individual, community and societal). Supplementary File 2 provides more details of the sources of evidence, noting which studies underpin each theme, and example quotations associated with each study.

Phases 2 and 3 – exploration of lived experiences of resilience

The findings from Phase 1 helped shape the development of questions for the stakeholder engagement activity in Phase 2, which sought the opinions of people living with dementia and carers (The Caban Group) on the topic of resilience. The qualitative themes and supporting quotes from the Phase 2 group discussion are presented in Supplementary File 3. Phase 3 built on the results of the previous two phases. Interviews began with participants describing what the word resilience meant to them, before exploring the concept further utilising a topic guide informed by the results of phases 1 and 2. Qualitative themes and supporting quotes from the Phase 3 interviews with people living with a rare dementia and carers are presented in Supplementary File 4. Example quotations from the thematic analysis are presented to provide evidence for each subtheme.

Table 2 provides the demographic information for phases 2 and 3. Participants (PLWD) in Phase 2 (male $n = 2$, female $n = 3$; mean age = 63) were diagnosed with AD or AD & VD several years previously ($M = 5.8$ years, range 3-8years). In Phase 3 there were a number of different diagnoses (see Table 2), with the most commonly reported being FTD; and a large range in time since diagnosis ($M = 3.6$ years, range 6 months – 8 years).

Phase 4 -Analysis and synthesis of phases 1-3 to generate a conceptual model of the key features of resilience in people living with dementia

Table 3 presents the synthesis of the themes relating to the experience of resilience for people living with dementia across the three phases, highlighting where corroboration and differences occurred which are discussed in the following narrative. This suggests a complex conceptual model of resilience for people living with dementia, where resilience is achieved through an interaction between resources present within the individual themselves, and other important resources external to the individual, at both community and societal levels. Supplementary Files 2-4 provide evidence in the form of example quotations to support the findings. Figure 3 visualises the model.

Threats to resilience

The devastating impact of the dementia diagnosis was a feature of discussion in phases 1 and 2. Participants in phase 2 describe experiencing a period post-diagnosis where they felt depressed and as if it was 'the end'. At this point, they would not have described themselves as being resilient. 'I've never bounced back. I feel really resentful that I've been handed this. But you also want, for family, to make the most of it as well.' (Phase 2, P1). There is acknowledgement in phases 2/3 that despite their resilience, participants also experienced depressive moments or days, but these could usually be remedied with, for example, self-care or encouraging words from family.

Some participants in phase 1 studies and phase 3 described keeping their diagnosis to themselves for fear of being treated differently, and phase 2 participants reported family becoming overprotective because of their diagnosis. Clarke and Bailey (2016) found whilst supportive, ongoing social engagement could also lead to a sense of embarrassment and estrangement through changes brought on by the dementia or environmental changes leading to recognition difficulties.

Difficulty accessing support is a related theme that was highlighted in phases 2/3. For phase 2 this involved not knowing where to access support, and in phase 3 related to a lack of appropriate services and support for those with rarer forms of dementia. Carers of people with more advanced rare dementias described resilience as something that may fluctuate and disappear as the disease progresses. 'Any idea of her having any sort of resilience would have gone by early 2017' (P2, phase 3).

The resilience reserve

'The resilience reserve' describes the assets and resources that may contribute to the capacity for resilience, at individual, community and societal levels. At the individual level themes reflect 'psychological strengths', 'practical approaches to living with dementia' and 'continuing with hobbies, interests and activities'. At the community level 'strong relationships with family and friends' 'peer support and education' and 'participating in community activities' were revealed. At the societal level 'the role of professional services' was deemed important.

Table 1. Description of studies included in the scoping review and resilience themes.

Authors	Participants	**Objectives (Methods)**	Resilience themes
Buggins et al. (2021) UK	8 people with dementia: 5 male, 3 female; age range 68–82 years (mean 72.9). 5 AD; 1 PCA; 1 LBD; 1 VD & AD. Ethnicity: All White British	To discover how older people's experiences of resilience in dementia are expressed through their personal narratives. (Qualitative interviews)	• Maintaining sense of humour. • Positivity, gratitude, hope and optimism. • Focus on what you can do. • Live for the day/in the present. • Maintaining pre-diagnosis activities. • Educating one's self / seeking information. • Participating in hobbies and activities. • Supportive carer. • Support from family. • Contact with others. • Advocacy and educating others about dementia. • Joining and being part of a group.
Casey and Murphy (2016) Ireland	6 people with dementia, mild-moderate stage, living in the community; 2 male, 4 female; 3 aged 60-69, 3 aged 70-79; 1-3 years experience of memory loss. Ethnicity: No information (the majority were born locally)	To explore what resilience meant for people with dementia and the factors that they felt aided or hindered it. (Qualitative interviews)	• Maintaining sense of humour. • Positivity, gratitude, hope and optimism • Faith / religious beliefs. • Participating in hobbies and activities. • Sense of purpose • Support from family. • Contact with others. • Advocacy and educating others about dementia. • Joining and being part of a group.
Clarke and Bailey (2016) UK	13 people with dementia, and a family member ($n = 12$). Dementia diagnosis range 1-10 years, most within 2 years.	Understand the importance of place in enabling resilience and citizenship, through exploring how people with dementia narrate their lives within individual and structural contexts. (Qualitative interviews)	• Focus on what you can do. • Maintaining pre-diagnosis activities. • Participating in hobbies and activities. • Supportive community resources.
Conway et al. (2020) UK	12 dyads. People with dementia – 10 male, 2 female; Dementia type – 5 mixed; 4 AD; 1 VD; 1 LBD; 1 unknown. Diagnosis 3 months – 6 years ($M = 2.9$ years). Age of people with dementia 67-89 ($M = 75.3$). Ethnicity: All White British	To explore what resilience means in the context of couplehood in dementia. (Qualitative interviews)	• Maintaining sense of humour. • Positivity, gratitude, hope and optimism. • Maintaining pre-diagnosis activities. • Adapting to new lifestyle/changing abilities • Participating in hobbies and activities. • Supportive carer. • Support from family. • Contact with others. • Joining and being part of a group. • Positive connections with healthcare professionals.
Halpin (2018) USA	2 people with dementia, 1 with MCI. Ethnicity: All White	To understand the factors that allow persons with cognitive impairment to adapt to their evolving MCI/AD status. (Secondary analysis of qualitative interviews)	• Acceptance of the diagnosis. • Openness about the diagnosis. • Adapting to new lifestyle/changing abilities. • Participating in hobbies and activities. • Sense of purpose. • Supportive carer. • Support from family. • Contact with others. • Advocacy and educating others about dementia • Joining and being part of a group. • Supportive community resources. • Religious activity.

(*Continued*)

Table 1. Continued.

Authors	Participants	**Objectives (Methods)**	Resilience themes
Harris (2008) USA	2 people with early-stage AD. Ethnicity: 1 African American, 1 Caucasian	To explore whether people with early-stage dementia can display patterns of resilience; What factors contribute to this process; how this adds to knowledge about successful ageing.	• Positivity, gratitude, hope and optimism. • Acceptance of the diagnosis. • Live for the day/in the present. • Faith / Religious beliefs. • Adapting to new lifestyle/changing abilities. • Practical adaptation. • Educating one's self / seeking information. • Participating in hobbies and activities. • A sense of purpose. • Supportive carer. • Support from family. • Contact with others. • Advocacy and educating others about dementia. • Joining and being part of a group. • Positive connections with healthcare professionals.
Harris (2016) USA	10 women with early-stage dementia (5 resilient, 5 not resilient, defined through observable positive outcomes in functioning and engagement in life) Ethnicity: No information	To explore whether women with early-stage dementia can display patterns of resilience; and what factors assist this process (Qualitative interviews)	• Positivity, gratitude, hope and optimism. • Acceptance of the diagnosis. • Focus on what you can do. • Participating in hobbies and activities. • Support from family. • Contact with others. • Advocacy and educating others about dementia. • Supportive community resources. • Religious activity. • Positive connections with healthcare professionals.
Pipon-Young et al. (2012) UK	8 younger people with dementia (age range 60-67). Time since diagnosis 1-5 years; 7 AD, 1 mixed dementia. Ethnicity: 6 White British. 1 White Asian, 1 Black other	To explore the experiences of younger people with dementia, understand beneficial support, areas in need of change, and key problems that need to be addressed. (Qualitative semi-structured interviews).	• Positivity, gratitude, hope and optimism. • Acceptance of the diagnosis. • Focus on what you can do. • Practical adaptation. • Participating in hobbies and activities. • Contact with others. • Advocacy and educating others about dementia.
Williamson and Paslawski (2016) Canada	7 people with dementia & 5 carers. Years since diagnosis <1-9. Montreal Cognitive Assessment (MoCA) scores range 12-19. Ethnicity: No information	To describe resilience in dementia, and identify factors that may influence resilience in dementia, from the perspectives of people with dementia. (Qualitative interviews)	• Maintaining sense of humour. • Positivity, gratitude, hope and optimism. • Acceptance of the diagnosis. • Openness about diagnosis. • Maintaining pre-diagnosis activities. • Adapting to new lifestyle/changing abilities • Practical adaptation • Educating one's self / seeking information. • Participating in hobbies and activities. • A sense of purpose • Supportive carer. • Support from family. • Contact with others. • Advocacy and educating others about dementia. • Joining and being part of a group. • Positive connections with healthcare professionals.

Table 2. Demographic characteristics of the research participants.

		Phase 2: Caban	Phase 3: RDS	
		People with dementia	People with dementia	Carer
Gender				
	Male	2	2	3
	Female	3	1	7
Age				
	Mean	63	74	63.7
	Range	51-76	67 - 81	51 - 70
Dementia diagnosis*				
	AD	3		
	AD & VD	2		
	PCA		2	2
	PSP		1	1
	FTD			4
	PPA			1
	FTD & PNFA			1
	DLB			1
Time since diagnosis				
	Mean	5.8 years (70 m)	2 years (24 m)	3.6 years (43 m)
	Range	3y-8y	6m-4y	6m-8y
Ethnicity				
	White British	5	3	10
Marital status				
	Single	1		
	Married	4	3	9
	Widowed			1
Lives with PLWD/Carer?				
	Yes	4	3	8
	No	1		2

*Dementia diagnoses: AD = Alzheimer's Disease; VD = Vascular Dementia; PCA = Posterior Cortical Atrophy; PSP = Progressive Supranuclear Palsy; FTD = Frontotemporal Dementia; PPA = Primary Progressive Aphasia; PNFA = Progressive Non Fluent Aphasia; DLB = Dementia with Lewy Bodies.

Individual/personal resources

Psychological strengths

Sub-themes around maintaining a sense of humour, a positive attitude, acceptance of the diagnosis of dementia, focussing on doing what you can (rather than deficits), openness about the diagnosis and living for the day were evident in all three sources of data (Supplementary Files 2-4). 'Once I learned to live with it, there are lots of things I can't do. But there are still lots of things that I can do, so that's the only way I can look at it' (P7 phase 3). 'Openness about the diagnosis' was perceived to lead to less personal embarrassment and increase public awareness and understanding. 'Living for the day' enabled people to focus on making the most of the present and not worry about the future. A strong 'spiritual or religious faith' was a crucial source of strength for some in phase 1 studies and phase 3. 'Comparison to others less fortunate' appeared within the individual interviews in phase 3 only. Participants spoke of other people facing difficulties or being 'worse off' than them, which seemed to bolster their own perceived resilience.

Practical approaches for adapting to life with dementia

Three sub-themes were found in all sources of evidence (Supplementary Files 2-4), which were: 'adapting to a new lifestyle or changing abilities' (e.g. shifting roles with carers, becoming more dependent on others), 'practical adaptation' (e.g. writing notes/lists, using devices for reminders), and 'educating one's self or seeking information' by, for example, using books, the Internet, support groups and dementia information sessions to gather more information about dementia and what to expect. The importance of 'maintaining pre-diagnosis activities' was highlighted in phases 1 and 3 (Supplementary Files 2 and 4), 'I walk to the allotment every day and I grow things, and I listen to classical music.' (Participant 4, person with dementia). Finding 'comfort in the ordinary' (such as watching TV, listening to music, having a coffee) was described in only phase 3 (Supplementary File 4).

Continuing with hobbies, interests, and activities

This theme was deemed important in all three phases (Supplementary Files 2-4). Varied interests included holidays, exercise classes, gardening, creative activities, baking, going for walks, and taking care of grandchildren, 'do the same thing that you've been doing before. Don't stop, activity is important.' (Williamson & Paslawski, 2016). Having 'projects' and the importance of having multiple interests were also described. Related to participation in hobbies and activities, 'maintaining a sense of purpose' was evident in phases 1 and 2, such as ensuring that one always has something to do, such as supporting and helping others.

Community resources

Strong relationships with family and friends

The importance of 'support from family and friends' for resilience in people living with dementia was highlighted in all three phases. Carers were found to be vital in providing support for maintaining daily activities. 'Supportive carers' who adjust alongside the person with dementia, accommodating for any changes, and continuing to involve them in plans and decision making were viewed as important in promoting resilience. Informal support from friends or family was often instrumental in aiding the person with dementia to adjust to their condition. Close long-term relationships with family, such as between parent and children, or with family who live nearby, are emphasised as being beneficial, as was the opportunity to spend time with children and grandchildren. The benefit of contact with others is described by numerous participants; people with dementia valued company, people to share problems with, and having new people in their lives who are non-judgemental of their situation. 'I can't express enough about friends, you must have a decent base of friends' (Conway et al., 2020).

Peer support and education- connecting with others affected by dementia

'Advocacy and educating others about dementia' were important in phases 1 and 2 (Supplementary Files 2 and 3). People were involved in educating medical students or other audiences to increase public knowledge and awareness about dementia. Helping others and contributing to advocacy work gave a sense of purpose, empowerment, and hope.

'Joining and being part of a support group' was discussed in all three phases as being instrumental in facilitating resilience for people living with dementia (Supplementary Files 2-4). Group membership provided people with knowledge of services, resources, and other supports. Groups involved with advocacy work provided people with a renewed sense of purpose, other groups provided a regular appointment and social opportunity.

Table 3. Synthesis of the themes across the three phases of research.

Themes	Phase 1: Scoping review	Phase 2: Caban group consultation	Phase 3: RDS interviews
Threats to resilience			
Depression, shock, confusion at diagnosis	√	√	
Denial to others / Worry about being treated differently	√		√
Family being overprotective		√	
Low moments		√	√
Difficulty accessing support		√	√
Lack of insight into dementia			√
Disease progression			√
Resilience reserve			
Individual resources			
Psychological strengths			
Maintaining sense of humour	√	√	√
Positivity, gratitude, hope and optimism	√	√	√
Acceptance of the diagnosis	√	√	√
Focus on what you can do	√	√	√
Openness about diagnosis	√	√	√
Live for the day/in the present	√	√	√
Faith or religious beliefs	√		√
Comparison to others less fortunate			√
Practical approaches for adapting to life with dementia			
Maintaining pre-diagnosis activity	√		√
Adapting to new lifestyle/changing abilities	√	√	√
Comfort in the ordinary (e.g. listening to music/TV/coffee)			√
Practical adaptation	√	√	√
Educating one's self / seeking information	√	√	√
Continuing with hobbies, interests and activities			
Participating in hobbies and activities	√	√	√
A sense of purpose	√	√	
Community resources			
Strong relationships with family and friends			
Supportive carer	√	√	√
Support from family	√	√	√
Contact with others	√	√	√
Peer support and education			
Advocacy and educating others about dementia	√	√	
Joining and being part of a group	√	√	√
Support from peers (living with dementia)		√	√
Participating in community activities			
Supportive community resources	√		√
Religious activity	√	√	
Societal resources			
The role of professional support services			
Positive connections with healthcare professionals	√	√	√

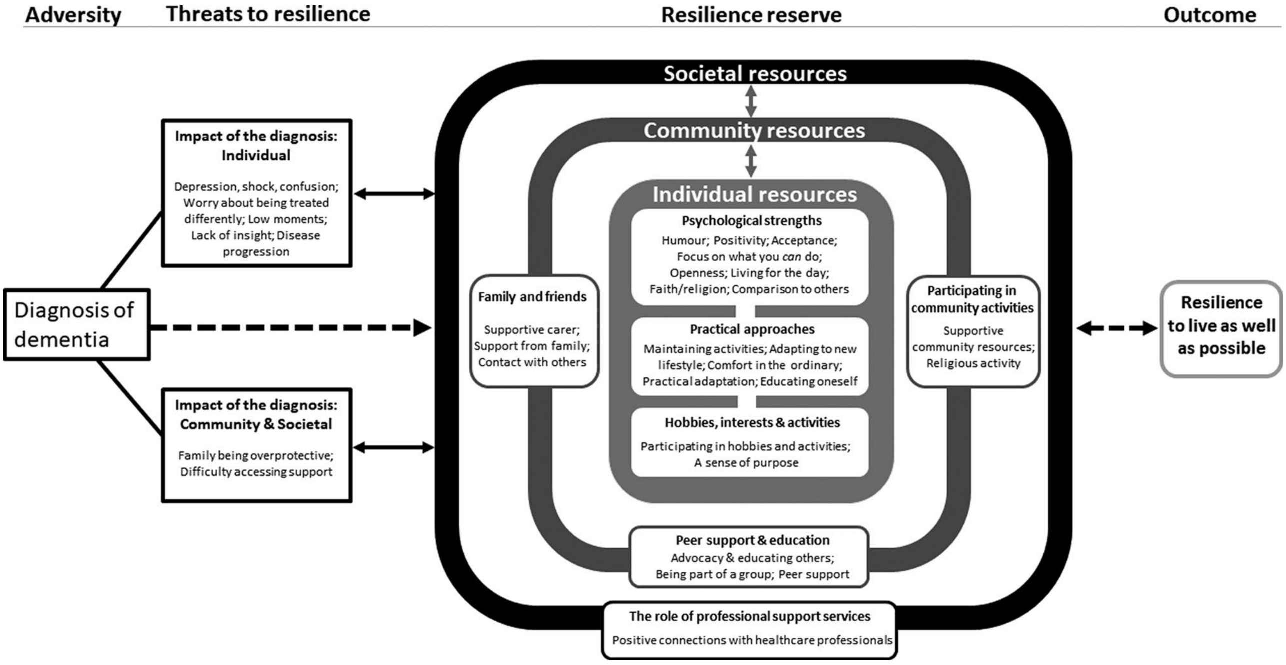

Figure 3. Conceptual model of resilience.

Related to group membership, participants in phases 2/3 (Supplementary Files 3 and 4) specify the importance of being connected to others living with dementia: resilience can be inspired by meeting others who are still living a good life with the condition. 'That's where my resilience has been built up, by meeting other people living, still having a life with dementia.'

[Phase 2 P2]. Others mentioned being in contact with others at a similar stage and sharing the journey together. Importantly, the majority of the comments in phase 2 (Supplementary File 3) noted changes following an unexpected 'chance' meeting, either with someone else living with dementia, or someone who could connect them with others living with dementia. These were a crucial turning point, providing them with a 'safety net', and all members of the group said their condition would have deteriorated if they had not occurred. Meeting others living with dementia and seeing what they could do gave people hope and motivation to do those things themselves, thus strengthening their resilience.

Participating in community activities

Evidence for 'supportive community resources' being conducive to facilitating resilience were provided in phases 1 and 3 (Supplementary Files 2 and 4). These included being a long-standing resident in a community, in terms of familiarity of place and also where members of the local community know and look out for each other (Clarke & Bailey, 2016). Participation in community groups and activities such as physical activity classes, church, support groups, community groups and volunteering were considered important for resilience in people living with dementia. Participating in community activities can aid the person to keep busy, be a means of social interaction can give the person a focus and purpose (Williamson & Paslawski, 2016), assist with acceptance of the diagnosis and continuing to live a meaningful life (Harris, 2016). There is some indication that religious activity and church attendance were deemed important in phases 1 and 2 (Supplementary Files 2 and 3) by, for example, providing backing to start up a support group or by means of the friendship felt within, e g. 'We go to [name of church] I've made so many friends, and they're so welcoming' (Phase 2, P1)

Societal resources

The role of professional support services

Positive connections and frequent meetings with services and supportive healthcare professionals were important in all three phases (Supplementary Files 2-4), and highlight how the threats to resilience at diagnosis can be mitigated. Access to excellent local services and supportive GPs were mentioned, e.g. 'we've got a very good GP who will refer us. If we go to him, he will refer us anywhere we want. He's great. So, he's onboard.' (Phase 3 P5), but only by a small number of people ($N = 5$). Within phase 3, guidance and advice provided by the Rare Dementia Support network was mentioned as being particularly helpful to those who were aware of this service. Beyond this, there was limited reference to the role of professional services in supporting the person.

Discussion

This work responds to the limited research to date regarding the experience of resilience for the person diagnosed with dementia and provides the first conceptual model of resilience specifically designed for and with people living with dementia. It also provides the first exploration of resilience in people with rarer forms of dementia. We show that resilience is possible when living with a dementia, although this may be a challenge in the more advanced stages. Resilience encompasses the day-to-day struggles of living with a dementia; people are not flourishing, thriving or 'bouncing back', but are managing and adapting under pressure and stress, as evidenced in phases 1-3 where people with dementia experienced depression and low moments alongside possibilities for resilience.

The synthesis suggests a conceptual model where resilience may be achieved through the collective and collaborative role of psychological strengths, practical approaches to adapting to life with dementia, continuing with hobbies, interests and activities, strong relationships with family and friends, peer support and education, participating in community activities and helpful connections with healthcare professionals. Resilience is described as an important aspect of the social health of people living with dementia (Dröes et al., 2017) and these findings add further insights into how resilience may underpin the three dimensions of social health: (1) the capacity to fulfil one's potential and obligations; (2) the ability to manage life with some degree of independence, despite a medical condition; and (3) participation in social activities (Huber et al., 2011). Supporting people living with dementia to engage in activities consistent with their preferred identities may support their resilience, as found in other in other populations exploring positive identity development (e.g. Bruce et al., 2015).

A meta-analysis has suggested the importance of other health conditions for people living with dementia (Martyr et al., 2018). We did not find this here, but this could be reflective of a healthier sample of participants. Alternatively, it could be that their resilience enabled them to mitigate the effects of any co-morbidity, as found in other studies of older people (e.g. Windle et al., 2020) and continue to be socially healthy.

Some tentative new findings are presented regarding the differing trajectories of resilience for people living with more common versus rare forms of dementia. Phases 1 and 2 highlight receiving the diagnosis as a threat to resilience, with people experiencing shock, depression, and confusion following a diagnosis. Importantly numerous people stated the lack of support from healthcare professionals, rather than the impact of the diagnosis itself were important factors. This included a 'disabling' diagnosis where the focus was on deficits and what could no longer be done. Consequently, the person giving the diagnosis can have a significant impact on the person's response and their post-diagnosis resilience. For those with rare dementia in phase 3 this may differ. They might experience a longer and more difficult route to an accurate diagnosis (O'Malley et al., 2019), but when the diagnosis is received, they may experience more feelings of relief and acceptance. For those living with rare forms of dementia the feelings of depression and confusion may be more prominent in the time preceding the diagnosis, during their search for answers, and often accompanied by multiple misdiagnoses (Novek & Menec, 2021).

Some other differences are also noted between data from phases 1 and 2, and those living with rarer forms of dementia in phase 3. For example, there is no mention of the theme 'advocacy and educating others about dementia' influencing resilience in phase 3. This may be due to there being fewer opportunities for people living with rare dementias to meet others living with similar conditions. Compared with memory-led dementias, understanding around rare dementias is relatively poor both among the general public and health professionals (e.g. Turpin, 2021), therefore inclusivity and understanding of rare dementias must be improved to better the societal and community level assets of those living with rare dementias. However, threats to resilience in phase 3 include lack of insight into symptoms (by the person with dementia) and disease progression, which suggests that the differences may be partly explained by stage as well as type, due to the input from carers of people with more advanced dementia.

The analysis was both deductive and inductive, initially applying an existing ecological resilience framework to help organise the findings and exploring what mattered the most for the resilience of people living with dementia across three phases of work. Although this framework was not designed for this purpose, it helped to highlight a number of factors important for resilience in people living with dementia to generate a new conceptual model. In dementia research, this framework has been mainly applied to understanding resilience in carers (Cherry et al., 2013; Donnellan et al., 2017; Han et al., 2019; Joling et al., 2016; Teahan et al., 2018), although Whelan et al. (2020) applied the framework in a review of interventions aiming to support resilience in people with dementia. Whilst their review identified only five interventions, these enabled access to resources that occurred at individual, community and societal levels. As noted by the WHO (2017b, p.4) ensuring resilience at these three levels requires environments that support health and well-being. Consequently resilience 'should always be seen in relation to the availability of such environments' (WHO, 2017b; p.31). Attending to the wider environment may also help reduce the amount of stigma experienced by people living with dementia, especially as in other populations stigma is suggested to reduce resilience, consequently reducing stigma may help increase resilience (Crowe et al., 2016).

Implications for practice

The findings from our research would point to health care professionals adopting different practices at the point of diagnosis. The Caban group in phase 2 proposed a more 'positive diagnosis' to minimise the impact and period of feeling low post-diagnosis, emphasising the importance of focussing on what you can do, and that this should be incorporated into the delivery of the diagnosis and post-diagnostic support services. We suggest working together with primary and secondary health and care services, people living with dementia and their carers to encourage methods of diagnosis delivery that can empower people to continue to live meaningful lives. Health and care providers could significantly impact on the resilience of people with dementia, emphasising a sense of hope and reassurance for a life with quality after diagnosis (Yates et al., 2021). Strengths-based approaches that facilitate the identification of assets and resources are recommended for national care policy delivery in the UK (SCIE, 2014). If used in conjunction with the conceptual resilience model, this would enable health and care professionals to identify where support may be most required and help create the supportive environments necessary to facilitate resilience. Following the discussion in phase 2, some of the participants wanted to share their experiences and a short video was created for other people living with dementia (https://www.youtube.com/watch?v=YJ1DRb_lqgk).

Future research considerations

There was a lack of ethnic diversity in the participants across all phases of the study and further research would benefit from more diverse samples to corroborate or augment the conceptual model, for example exploring how resilience is experienced in different cultures. As the findings of this study are derived from cross-sectional study designs, longitudinal studies could explore how resilience is experienced over time. For example, a longitudinal study showed that mental health resilience significantly predicted lower levels of loneliness over time in people with cognitive impairment (Windle et al., 2021) suggesting how resilience might influence important health outcomes.

The domains of the new model share similarities with 10 of the 13 core outcomes deemed important to people with dementia living at home that should be measured in all intervention research ('importance of relationships', 'communication', 'feeling safe and secure', feeling valued and respected by others', 'meaningful activities', 'apathy/indifference' described as keeping interested in things, 'understanding time and place', 'stability', 'a sense of who you are' and 'having a laugh', Reilly et al., 2020). The authors note these core outcomes should be measured in evaluations of non-pharmacological and community-based health and social care interventions for people with dementia living at home. Relating these core outcomes to resilience, standardised resilience measures have been developed for other populations, but most are limited in focus to the individual/psychological resources that enable resilience (Windle et al., 2011). Our research provides an argument to consider resilience beyond the individual. It suggests the development of a measure of resilience with, and for, people with dementia informed by our findings would address a major research gap. This could have the additional advantage of efficiently capturing a substantial number of the core outcomes identified by Reilly et al. (2020) in a single measure as opposed to administering multiple outcome measures.

Strengths and limitations

The iterative process of primary and secondary research across three discrete phases explored lived experiences to generate new knowledge and deepen the recognition that for some people, resilience is possible when living with a dementia. However, as a relatively under-explored area of research, the scoping review yielded a limited number of studies, predominantly with small numbers of participants in developed nations. Most studies lacked detailed diagnosis information, therefore it is possible that different levels of severity and dementia types may yield more diverse findings around resilience. Phase 3 included several 'proxy' accounts from carers of people living with advanced dementia which helped add further insights, but assessing resilience in people with moderate to advanced dementia is a challenge (Whelan et al., 2020). Although unlikely to be a completely accurate substitute to the account of the person with dementia themselves, we suggest that proxy accounts can be useful. Further investigation is warranted as this raises the question of how to explore resilience, and whether it is achievable, in advanced dementia. Further theory building from the conceptual model developed in this research could underpin the extent to which resilience in people living in care settings could be measured using techniques such as behavioural observation.

Other participant characteristics may also influence the findings. For example, some participants in the scoping review studies were recruited from the Alzheimer's Society who encourage members to be open about their diagnosis (e.g. Williamson & Paslawski, 2016). The Caban Group in phase 2 were involved in advocacy work, so educating and helping others were strong themes for them. And lastly, those interviewed in phase 3 were members of the RDS network, therefore the importance of peer support and group membership was naturally highlighted.

Conclusions

This work contributes new insights regarding resilience from the perspectives of people living with dementia, and the research methods ensured the emergent conceptual model is relevant to, and grounded in, the personal experiences of people living with a dementia. It shows that resilience is not just a psychological attribute but requires the combined interplay of internal and external resources across multiple levels. Focussing on resilience does not seek to downplay the devastating impact of dementia for many people. Rather this work suggests how, in the absence of a cure and limited medical treatments, improvements could be directed at the point of diagnosis and post-diagnostic support to not only improve that experience but also explore the different domains of resilience as revealed in our study. 'Bouncing back' may be unrealistic, but re-framing conversations during diagnosis could support those affected by the condition to live as well as possible and achieve resilience through appropriately tailored services and support. If delivered earlier in the trajectory of dementia, it could help a person remain resilient longer. Arguably, a 'resilience practice' approach could extend to other degenerative or debilitating chronic conditions a person faces in their life course.

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Disclosure statement

The authors report there are no competing interests to declare.

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