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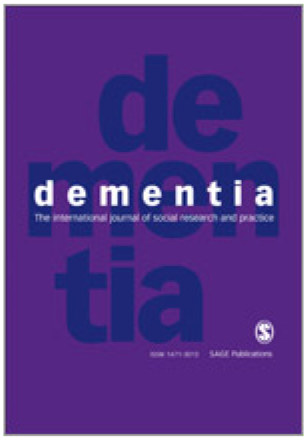

Resilience in older people living with dementia – A narrative analysis

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Abstract:	Dominant discourses surrounding dementia tend to focus on narratives of loss and decline. Simultaneously, individuals living with dementia are vulnerable to being dispossessed of personal narratives supportive of identity and well-being. How older people with dementia story their experiences of resilience in this context has not previously been investigated. In response, this qualitative study utilised a narrative approach to understand lived experiences of resilience shared by eight older people living with dementia. Structural analyses indicated that participants' personal narratives regarding resilience in living with dementia contained distinct and common phases (The Diagnosis, Initial Tasks, The High Point, Reflecting on Limitations, and Focusing on Today) as well as a variety of dynamic characters. Overarching themes within participants' narratives included sense of self / identity, being connected to others, sense of agency, and having positive attitudes. Participants narrated richer, more active personal stories than those typically represented in dominant social discourses surrounding dementia. As such, their narratives depict lived experiences of resilience that unfolded over time in response to adversity and uncertainty and involved a dialectical process in relation to adjustment and well-being. The findings have important implications for the way resilience in living with dementia is framed and supported.

Abstract

Dominant discourses surrounding dementia tend to focus on narratives of loss and decline. Simultaneously, individuals living with dementia are vulnerable to being dispossessed of personal narratives supportive of identity and well-being. How older people with dementia story their experiences of resilience in this context has not previously been investigated. In response, this qualitative study utilised a narrative approach to understand lived experiences of resilience shared by eight older people living with dementia. Structural analyses indicated that participants' personal narratives regarding resilience in living with dementia contained distinct and common phases (The Diagnosis, Initial Tasks, The High Point, Reflecting on Limitations, and Focusing on Today) as well as a variety of dynamic characters. Overarching themes within participants' narratives included sense of self / identity, being connected to others, sense of agency, and having positive attitudes. Participants narrated richer, more active personal stories than those typically represented in dominant social discourses surrounding dementia. As such, their narratives depict lived experiences of resilience that unfolded over time in response to adversity and uncertainty and involved a dialectical process in relation to adjustment and well-being. The findings have important implications for the way resilience in living with dementia is framed and supported.

Keywords

Dementia; Resilience; Narrative; Identity; Well-Being

Introduction

Social and scientific discourses surrounding dementia are heavily influenced by narrow biomedical perspectives that prioritise the search for treatments capable of stopping or reversing neurodegeneration. In the ongoing absence of a medical cure, however, such discourses can also inadvertently fuel hopeless and nihilistic narratives (Behuniak, 2011; Van Gorp & Vercruysse, 2012) which focus on losses and deficits. Accordingly, there is a need to develop alternative narratives which fully recognise the personal and social strengths and assets of people with dementia and which therefore advance clinical research and public policy (Bailey et al., 2013; Harris & Keady, 2008; Wolverson, Clarke & Moniz-Cook, 2016).

Living well with dementia is likely to involve multiple psychological factors (see Clare et al. 2018) but applying the construct of resilience may be fruitful. Resilience can be conceptualised as a buffer against adversity (Ong, Bergeman, & Boker, 2009) or as a process of ‘bouncing back’ from adversity (Netuveli, et al., 2008, p.958). Resiliency perspectives draw attention to the accumulation of assets and protective factors over the life-span, which can facilitate well-being in the face of adversity in ageing (see Richardson, 2002; Pruchno, Heid & Genderson, 2015). Resilience can therefore underpin adaptation to age-related challenges (Allen et al. 2011) and is associated with a greater sense of coherence, purpose in life, self-transcendence and quality of life in ageing (Nygren et al., 2005; Netuveli & Blane, 2008) as well as reduced depression (Wermelinger Avila, Lucchetti & Lucchetti, 2017). Resilience in dementia caregiving has been explored to some extent (Donnellan, Bennett and Soulsby, 2015) but relatively little research to date has explored experiences of resilience amongst people living with the condition.

Harris (2008) conducted the first study to explore subjective experiences of resilience amongst people living with dementia. Utilising a case study approach (n=2), her findings suggest that resilience is relevant to understanding living with dementia and is connected with access to personal and social resources that protect against threats to identity and well-being. More recently, Williamson and Paslawski (2016) explored the meaning and experience of resilience for 7 people with dementia along with their care partners. Thematic analysis indicated 3 interacting themes in how participants experienced resilience in dementia; active and purposeful living, perspective and [accessing] resources. Clarke and

Bailey, 2016, also explored resilience in people living with dementia (N=13). They explored resilience over a 12 month period, and found that it linked to people's perceptions of being socially included and supported.

Harris (2016) presents further evidence that a person's sense of resilience can be preserved in dementia and that high and low levels of resilience may reflect interactions between retained assets/resources at personal, interpersonal and community levels. Such work raises important questions about how people sustain resilience in living with dementia over time, what characterises this subjectively and how it is best facilitated (see Harris, 2016).

Narrative approaches offer insight into these processes. Personal narratives, the stories we tell about ourselves (to others and to ourselves) help us construct and communicate meaningful representations of our identity and autobiography over time (Rosenthal, 1993; Randall, 2012; Pasupathi & Mansour, 2006). They hold particular value in understanding the ways that people sustain well-being, even in the context of life-altering circumstances (Carless & Douglas, 2017). In a pertinent illustration of this, Randall et al. (2015) examined structural and thematic differences in personal narratives for 20 older people scoring high and low on the Connor-Davidson Resilience Scale (Connor & Davidson, 2003). They reported that those scoring high in resilience provided personal narratives characterised by experiences of adversity but which were also more likely to be counterbalanced by positivity, openness, autobiographical reasoning and spiritual connectivity.

People with dementia are arguably vulnerable to being dispossessed of such positive personal narratives. This may occur due to progressive cognitive impairments in language and memory but also via negative social processes that result in experiences of alienation and perceived loss of value (Patterson, Clarke, Wolverson & Moniz-Cook, 2017). In addition, 'healthy' narratives are typically framed in terms of health and autonomy, which inevitably disadvantages people living with cognitive impairments (see Baldwin, 2006). Supporting people with dementia to tell their own personal stories therefore provides an important opportunity to understand experiences of resilience whilst also promoting agency and re-connection with narrative identities (Purves et al., 2011). However, no research to date has considered the experience of resilience in dementia from a narrative perspective. This study therefore used a narrative approach to elicit stories of resilience from a sample of older people living with dementia, the aim being to enhance our understanding of how resilience is represented and *lived* in dementia.

This research asked;

- How are older people's experiences of resilience in dementia expressed through their personal narratives?
- What key themes characterise such narratives?
- How are these narratives structured and conveyed in terms of plot, characters and tone?

Method

Design

Qualitative methodology was utilised to obtain narratives of resilience from older people living with dementia. Data was collected through face-to-face interviews, where participants were asked to share their personal stories of resilience in living with dementia.

Sampling

Purposive sampling was used to recruit voluntary participants from community settings in the North East of England. To recruit participants, the lead researcher (SB) attended a range of support groups organised by voluntary sector organisations for people with dementia, advertising the study through face-to-face discussions and the use of posters and information sheets. When a group member showed an interest in participating, SB collected their contact details and telephoned them on an agreed date to confirm participation. Once confirmed, a face-to-face meeting was arranged to complete the interview.

Participants were invited to take part if they were 65 years of age or older, living with a self-reported diagnosis of dementia, willing to consider and discuss the issue of resilience and could speak English with enough confidence to share their story. Participants under the age of 65 were not included, in line with both research and clinical practice highlighting that the experience of dementia appears to be qualitatively different in younger people, and warrants separate study (e.g. Clemerson, Walsh, & Isaac, 2013; Rabanal, Chatwin, Walker, O'Sullivan, & Williamson, 2018).

Participants needed to have capacity to consent to participate in this research (Warner, McCarney, Griffin, Hill, & Fisher, 2008), needing to understand what it involved and what it was about (i.e. providing stories about resilience in living with dementia). This was evaluated clinically by SB at the point of recruiting and gaining consent.

Participants were not included if they had received their diagnosis within the preceding 12 weeks, as research suggests that key adjustment processes occur within this time (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006) and this study was focused on the ongoing process of living with dementia rather than adjustment to a diagnosis.

Procedure

The study was granted ethical approval from the University of Hull Research Ethics Committee (UK).

All interviews took place in participants' homes, as preferred by participants. Detailed information about the study was provided to each participant verbally and in written formats. This included explicitly stating that the study was focused on exploring people's experiences and personal stories of their own resilience. Prior to sharing their story, participants provided written consent and shared demographic information. Participants were informed of their right to withdraw and were assured that the audio recording of their story could be stopped at any point. Participants were also reassured that there were no 'wrong' responses and no required length of time for the meeting, as this would naturally depend on how long it took for them to share their story.

In accordance with narrative methodology, structured questioning was not used (Josselson, 2011) and a particular pre-established definition of resilience was not imposed on participants. Instead, resilience was operationalised broadly in relation to how participants had responded and adjusted to adversity related to dementia. To start, participants were provided with a short statement which framed the study in terms of personal stories of resilience:

"This study is about resilience. I would like to ask you to tell me a story about how you have responded to changes and challenges since your dementia diagnosis. Each story should have a start, a middle, and an end. This is your own personal story and there are no right or wrong answers or things to say. Please tell me a story about how you have responded to challenges and changes since being diagnosed with dementia”. Simple verbal prompts (e.g. “what did you do?”, “why?”, “how did you do it?”, “what helped?”) coupled with active listening were used to facilitate the sharing and construction of participants’ stories of resilience. No time limits were imposed.

Analysis

Participants’ stories were subject to a combination of structural, performative and thematic narrative analyses, based upon methods described by Riessman (2000, 2008) and the typology outlined by Phoenix, Smith and Sparkes (2010) for narrative analyses in studies of ageing. We adopted a social constructionist epistemological stance, recognising each narrative as being a representation of one of many truths (Miller, 2006). As a younger female with both personal and professional experience of dementia, the lead researcher (SB) acknowledged that her role as interviewer, as well as the common presence of participants’ spouses during interviews, shaped how stories were told and this effectively led to narratives that were co-constructed (Riessman, 2000, 2008).

In order to ensure rigour and validity, interviews and transcripts were listened to and read repeatedly. Interpretations and observations were noted by the first author, and were examined by the other two authors through regular supervision. The first author also attended several qualitative research peer group meetings, to reflect on the analytical process. A case-by-case approach was utilised initially, whereby each narrative was temporally ordered (i.e. in terms of chronology of the events discussed). Next, all events, emotions, characters and the relationships between these components were highlighted (Smith & Sparkes, 2009; Phoenix et al., 2010), to enable the identification of narrative plots and tone. Plots were then compared across participants, and were integrated to assess divergence and to determine commonalities (i.e. to highlight common themes and to identify a master narrative; Riessman, 2008) across participant’s differing experiences.

Results

Participants

Nine individuals were invited to take part in the study but one person was excluded after showing initial interest as they did not subsequently self-identify as having a dementia diagnosis. The final sample comprised eight individuals living with dementia; five men and three women, with an age range of 68-82 years (mean 72.9).

All participants classed themselves as White British, and all lived with a long-term heterosexual partner. All reported regular social contacts, seeing friends or family more than once a week. Further details about participants are displayed in Table 1. Pseudonyms are used to maintain anonymity.

Six participants chose to have their spouse with them during the meeting. Each spouse contributed to their partner's story at times, sometimes in response to an invitation to join from the participant, and sometimes choosing to join themselves. These contributions were not analysed as the study focussed on the experiences of people living with dementia.

Table 1: Participant details

Pseudonym	Age	Type of dementia	Time since diagnosis
Brian	69	Vascular & Alzheimer's disease	6 months
Henry	79	Alzheimer's disease	15 months
Julie	71	Posterior cortical atrophy	4 years
Mary	73	Alzheimer's disease	8 months
Susan	68	Alzheimer's disease	2.5 years
David	73	Lewy Body dementia	7 years
Robert	82	Alzheimer's disease	4 years
Leonard	68	Alzheimer's disease	5 years

Narrative Features

Participants' stories lasted between 7 and 31 minutes, with an average story time of 18 minutes. Stories varied slightly in terms of speed of narration and fluidity. Analysis revealed a number of structural phases, significant characters, and convergent themes present across narratives. Participant quotes are used to illustrate the findings. Words emphasised by participants are underlined, words added by the researcher for context or to ensure anonymity are enclosed in [ ], whilst […] represents omitted text.

Characters

Several significant characters were present within and across participants' narratives of resilience (Smith & Sparkes, 2009; Stout, 2016). Participants usually positioned themselves as the main protagonist of their story, usually playing dynamic characters with a variety of emotions, challenges, and roles. At times they played a passive role, awaiting support from medical professionals and drugs companies, but on the whole participants took an active role. Spouses were positioned in the role of the 'sidekick', loving, supportive and dependable. The importance of this role was evident in how participants frequently positioned themselves as a couple, repeatedly using the 'we' pronoun, and how they frequently invited their spouses to join as a secondary storyteller. This conveyed a sense of togetherness between participants and spouses. At other times, participants strove to maintain their autonomy and individual identity through using the "I" pronoun and positioning their spouses either next to or behind them at various key phases (see below). Other characters included wider family and friends with supportive roles, medical professionals, who were often positioned as antagonists, whilst charity organisations were supportive protagonists. Dementia itself was positioned as a key antagonist, but played a dynamic role, with its presence, amount of perceived control over it, and the level of threat it represented changing over time.

Thematic analysis

Participants shared different experiences, but similar *kinds* of stories were identified, with convergent themes and sub-themes emerging (Table 2). Overarching themes were; 'sense of self', 'being connected', 'sense of agency', and 'outlook on life'. Themes had a particular presence within certain narrative phases and are further discussed alongside the structural findings.

Table 2: Overview of themes emerging from resiliency narratives

Themes	**Subthemes**	**Example quotations**
Sense of self	Continued identity	***'I'm still here'*** (David)
	Evolving identity	***'I will go into my old age grey-fully gracefully'*** (Brian)
	Self-identity vs. shared identity	***'[My wife] will go with me, but I'm in the choir'*** (Henry)
Being connected	Spousal relationship	***'if it wasn't for [my wife] it would be a different story'*** (Leonard)
	Wider relationships	***'I've got good friends you see, so it's alright'*** (Mary)
	Feeling supported	***'there's a lot of good work being done by people…that makes a big difference'*** (Mary)
	Contributing to the community	***'I go out and I help other people'*** (Julie)
Sense of agency	Seeking knowledge	***'I've asked a lot of questions. I've asked why, where, what and when'*** (Brian)
	Keeping	***'Once you do it, it makes you want to do more. And I***

	busy	***do, I am doing as much as possible'*** (Julie)
	Aware of issues and making adjustments	***'I haven't played since, not, not that, but now I'm playing croquet'*** (Robert)
	Learning from challenges	***'…it's like life, there's always a challenge round the corner'*** (Brian)
Outlook on life	Humour	***'Another thirty year I might be calling might call myself an old age pensioner *laughs*'*** (Brian)
	Focus on the present	***'I go on now and just enjoy what I've got left'*** (Julie)
	Positive attitude	***'So I'm just content quite honestly'*** (Henry)
	Gratitude	***'I've said for years…I'll be really glad if I get, if I get to seventy'*** (Brian)

Structural Analysis

Although each person's specific experiences differed, for seven participants the structural elements of their resiliency narratives reflected five common temporal phases; 'The diagnosis', 'Initial tasks', 'The high point', 'Reflecting on limitations', and 'Focussing on today' (Figure 1). For Leonard, the first two phases were not evident in his story. Instead, Leonard's narrative began at 'The High Point'. Rather than emerging as discrete and sequential stages, participants' narratives fluidly moved between phases, sometimes returning to an earlier phase before moving forwards and reaching the final phase of ‘Focussing on today’.

The narratives of the seven participants who described all five phases reflected an overarching storyline and shift in tone consistent with Frye’s (1957) tragic romance, characterised by underlying feelings of nostalgia, loss and fear that were eventually absorbed by experiences of meaning through the actions of the protagonists. In contrast, Leonard’s story was more reflective of a romance, starting at ‘The High Point’ and declining in narrative mood before inclining again as the story closed (Frye, 1957).

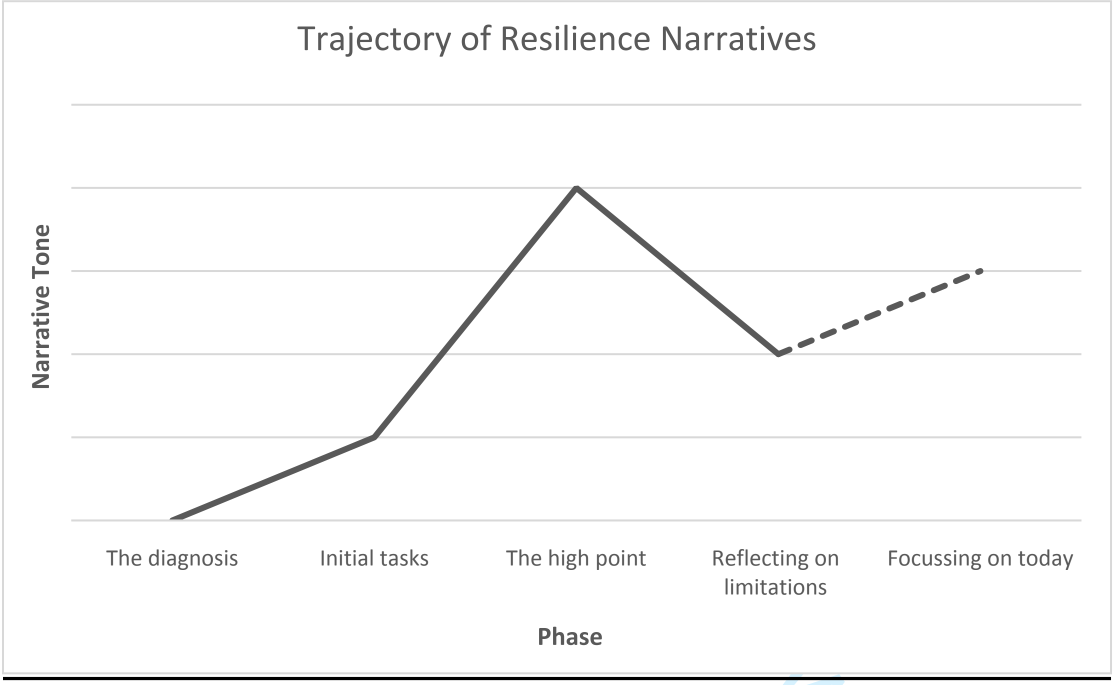

Figure 1: Trajectory of Resilience Narratives; Temporal Phases and Narrative Tone (n=7)

Phase 1: The diagnosis.

The first phase, present for seven participants, described events leading up to, and immediately following, receiving a dementia diagnosis. This phase was characterised by shock, confusion, and loss of agency, with dementia positioned in the foreground as a source of adversity. Dementia represented the key antagonist for participants at this stage and therefore represented the lowest point of narrative tone on the trajectory within all seven narratives. Most participants positioned themselves in a passive role and began their story by describing how they noticed early changes in their abilities. For Henry, this centred on an early awareness of memory difficulties and an acknowledgement of related challenges;

'I er kept forgetting things, leaving things on the train'

(Henry)

Most participants described the assessments they completed, although two stories began at the stage of receiving their results. Participants particularly recalled feeling dismissed following their diagnosis, with medical professionals often playing key antagonists at this point;

'I think it was at [the] clinic…I must have gone there about two, three or four times, then towards the end they just errm, that was it. There was no other background…it just finished like, you know. Just like that, you know. "Well that's it. That's your lot'"

(David)

Several participants described their personal responses following diagnosis, with these initial reactions reflecting their "state of shock" (Mary) and distress;

'it was mind blowing and I got up, [doctor] said "where you going?" I said I don't know, I said I just wanna go…ten minutes later I went back and said I'm sorry about that'

(Brian)

Phase 2: Initial Tasks.

This second phase described the meaningful instrumental tasks carried out by participants following the shock of diagnosis. The trajectory of the tone of the narratives seemed to incline in this phase, reflecting a re-gaining of agency. Some participants reached this phase quickly;

'…we got home we just cried and laughed and cried and said "what now"?'

(Brian)

Others described a slower process of reaching this phase;

'For a while we were just sad, wondering what the devil to do…until errm a lady from Age Concern came to see us'

(Henry)

This phase saw participants seeking knowledge around available support, and a strong theme of agency emerged as participants strived towards their goals;

'I've asked a lot of questions. I've asked why, where, what and when…and you know everything was sorted financially and securely within 6 weeks'

(Brian)

Charity organisations were introduced by all participants at this point and played a protagonist role, being described as 'marvellous' (Brian) and 'very helpful' (Mary), with Henry reporting their help 'lifted me up'. Participants talked positively about joining such organisations;

'I've sort of got lots of leaflets on those…we quite like his dementia café that's at the hall…we usually go there regularly'

(Mary)

Phase 3: The high point.

This phase reflected a peak in the narrative trajectory, emphasising participants' positive and optimistic moods. It was the first phase to be described in some way by all participants, and was characterised by a sense of busyness and growth, with an overarching theme of 'being connected' emerging. Brian stated that since his diagnosis he has 'started doing things now that I've never done before'. This was echoed in other stories, with new activities including glass edging (Brian), speaking at dementia conferences (Henry), volunteering at charity fundraisers (Julie), starting dance classes (Mary), and starting to play croquet (Robert). Several participants also talked about ensuring that they continue to do things that they have always done. For example, Leonard continued attending French classes;

'When you've spent years and years speaking it, it's a bit silly to lose it'

(Leonard)

Most participants talked about new relationships that have formed because of their dementia diagnosis, with new characters entering their stories. Most talked about gaining new friends and meeting people through support groups, whilst Brian focussed more on how the diagnosis helped him to reconnect with family. Several participants also described how they enjoy helping others in the wider community, emphasising the importance of mutual support. For example, David received his dementia diagnosis seven years ago and shares his experiences with people newly diagnosed;

'I think I'm helping some others as well…a lot of the people want to know what's coming'

(David)

During this phase, all participants positioned dementia in the background, rather than as an active antagonist;

'Sometimes I don't feel as if there's anything wrong with me'

(Henry)

In contrast, a sense of activity, connection, and enjoyment in life was in the foreground;

'…that's the singing for the brain group…it's just really fitting things in, you know, with your life'

(Mary)

Phase 4: Reflecting on limitations.

Following the peak in phase three, participants moved on to reflect upon the current limitations posed by dementia and the ways they seek to manage these. Dementia returned to the foreground;

'I mean I know what's what. I know what I can do and what I can't do'

(Henry)

This phase was characterised by an awareness of the daily challenges that participants encounter;

'I get annoyed with myself you know…somebody will come and tell me their name and I bet by the time they're going out of the door it's gone'

(Robert)

However, interwoven with this awareness were examples of how participants manage their limitations. Whilst participants' specific examples differed, a strong theme of agency was present throughout all narratives, with a sense of having some control over dementia;

'…if I get really fed up I get up and do something, I don't just sit and dwell…I don't let it get hold of me like that'

(Susan)

Other examples included how Brian talked about not letting things 'mingle round' his head, David stated 'I don't sit around feeling sorry for myself', and Julie reported;

'…what you've got you've got to do yourself, and enjoy yourself…I don't sit here and cry'

(Julie)

In this phase, participants also described sources of confidence in their ability to overcome acknowledged limitations. For Robert and Leonard, their spouses played a prominent role as sidekick. Others drew upon previous ways of coping and lessons learnt through past experiences;

'I think I'm more calmer…if anything went wrong I don't go around getting upset and all that lot…but that's the way it is like in the building trade, you know, you just move on'

(David)

The importance of attitude and outlook on life emerged as a convergent theme across all narratives, with participants emphasising the importance of positivity, gratitude, humour, and staying calm;

'I'm lucky you know with our family'

(Mary)

Within this, participants' narratives conveyed their attempts to maintain a sense of resilience through comparisons between themselves and other people living with dementia perceived to be less resilient. As such, participants, talked about other people's 'lack of confidence', their 'denial' (Brian), or how 'they just sit at home and just don't do anything' (Henry). Similarly, others expressed the belief that 'a lot of people don't want to join [things]' (Mary), and that others may have less resilience because they have less life experience;

'...they couldn't really cope with it...they're maybe a bit younger than me'

(David)

Phase 5: Focussing on today.

This final phase was characterised by a positive sense of focussing on the present but within this was also a significant sense of uncertainty about the future. This final phase often involved participants reflecting on life in general;

'As I say, I'm eighty in January, I could be gone before it gets any worse, you know. So I'm just content quite honestly'

(Henry)

Across narratives there was an awareness of the progression of dementia, with the future often portrayed as threatening and associated with anticipated loss;

'...it doesn't occur to me to be depressed yet. I just think well now you know I can have a conversation with people, perhaps you know when it gets further on I might go through times like that'

(Mary)

Alongside this sense of future threat, participants expressed their need to retain a sense of identity;

'...but I'm still here!'

(David)

Participants also continued to emphasise the importance of their outlook on life, portraying a strong sense of remaining positive and living for today;

> *'I think, just to sum it up, is to just act as I am now…with one day at a time, and err see how many days that lasts, because it will be a long time'*
>
> *(Brian)*

Participants' stories tended to end abruptly, which made it difficult to assess the final mood of the narrative although the general trend inclined (Figure 1). Narrative endings often conveyed a central message relating to an intended continuation of a personal sense of resilience. For example, Susan ended her story stating that she will 'just go with the flow', whilst David stated 'I will last a long time'. Julie's story ended with a general reflection on how she lives her life, recommending that others 'try and live it up as much as you can'.

Discussion

The stories that we tell about ourselves and our lives reflect those stories as they are lived (see Williams & Keady, 2006). As such, personal stories of living with dementia convey rich lived experiences and complex meanings that are not easily captured. Eliciting personal stories promotes empowerment by seeking to enable people to retain the possession and expression of 'thick' stories (Randall, et al. 2015) that reflect complex interactions between positive and negative aspects of their own lived experiences (Werezak & Stewart, 2009; Purves, 2011). The documenting of personal narratives about resilience also contributes to broader asset-based social narratives about how it is possible for people to live well with dementia. This resonates with research concerning the psychological and social factors involved with living well (Clare et al. 2018) as well as emerging social citizenship and empowerment perspectives (Clarke & Bailey, 2016).

To our knowledge, this is the first study to analyse how older people living with dementia construct personal narratives about experiences of resilience. The narratives provided by the participants in this study are vivid and multi-faceted, reflecting intricate plots, characterisations and changes in tone that are experienced over time. They demonstrate how agency and identity might contribute to an experience of resilience that is a dynamic, unfolding process rather than a discrete outcome of adjustment (see Ryff & Singer, 2003).

Furthermore, participants' narratives of resilience involved an awareness and use of personal assets and protective factors, consistent with existing findings (e.g. Williamson & Paslawski, 2016). Participants expressed individual trajectories of resilience with unique experiences, but underlying this there were strong thematic and structural commonalities, perhaps in part owing to the shared influence of supportive protagonists and the wider community (see Clarke & Bailey, 2016). The salience of 'being connected' for participants highlights how perceived support and reciprocity in social relationships could play a key role in the experience of resilience in dementia (Vernooij-Dassen, Leatherman, & Rikkert, 2011). This is noteworthy since models and measures of resilience tend to focus on individual traits and strengths rather than social resources (Windle, Bennett, & Noyes, 2011). As such, there is a need for further research to further explore the interpersonal and social dimensions of resilience as experienced by people with dementia (e.g. Yorgason, Piercy, & Piercy, 2007) and how these can be best facilitated.

Narratives of resilience shared by these older people living with dementia weaved elements of loss with growth, passivity with proactivity, and fear with pleasure. Stories were multi-dimensional and far richer than those typically conveyed by dominant negative discourses surrounding dementia. The narratives appeared to represent a dialectical process involving the 'negative and positive aspects of living' (Ryff & Singer, 2003; p. 272). On the one hand, wider discourses around dementia involving loss, fear and pathology (Bender, 2014) were represented in participants' narratives of resilience. Narrative themes relating to searching for a medical cure and losing aspects of self-identity were present, echoing common themes in social and media-level dementia narratives (Van Gorp & Vercruysse, 2012). However, each person's resilience narrative also focussed on using personal strengths and resources as they made their own 'journey' through dementia. Humour and gratitude appeared to be key aspects of this, reflecting their preservation and functions in living with dementia (see Hickman, Clarke & Wolverson, 2018; Pearson, 2017).

Through their stories, participants positioned themselves as dynamic characters, with a preserved self-concept, who attempted to become more autonomous over time. This resonates with the notion that autobiographical reasoning is linked with resilience in ageing (Randall et al. 2015) but also that people with dementia embark on a process of personal adjustment after receiving a diagnosis of dementia that involves seeking a sense of continuity (Werezak & Stewart, 2002) whilst maintaining a positive sense of self and identity (e.g. Pearce, Clare & Pistrang, 2002). As resilience emerged, participants attempted to negotiate this process from a stance of self-determination and effectively re-positioned dementia in their narratives as they unfolded, from foreground initially to relative background over time. This is in line with Paterson's (2001) shifting perspectives model of adjustment; some people living with a long-term illness are able to re-position their illness to the background (i.e. re-prioritise its salience) in order to maintain meaningful goal pursuits and wellbeing.

Previous research findings (e.g. Williamson & Paslawski, 2016; Harris, 2008; Casey & Murphy, 2016) suggest that people with dementia experience resilience in terms of drawing upon social and psychological assets to maintain continuity in meaningful activities and sense of self. The source of resilience can link to a sense of gratitude; a thankfulness for the life lived (Casey & Murphy, 2016). This sense of continuity and 'keeping going' was also a feature of participants' resiliency narratives in this study, however, aspects of the structure of participants' narratives also suggests the potential relevance of a 'bouncing back' (Netuveli et al., 2008, p958) account of resilience. Consistent with the findings of Randall et al. (2015) a sense of resilience for our participants appeared interwoven with the experience of adversity. For the majority of these participants, feeling resilient emerged over time *in response* to the adversity of receiving a diagnosis, rather than acting as a buffer from the beginning. Importantly, rather than solely relating to the impact of receiving the diagnosis itself, the low narrative mood at the beginning of the majority of the stories was associated with strong feelings of being dismissed by medical professionals following their diagnosis. This highlights a key role for clinicians and services in providing structured and high-quality post-diagnostic support that fosters resilience for people with dementia as they follow a process of adjustment (Vernooij-Dassen et al., 2006). In particular, life story approaches have the potential to facilitate resilience by bolstering narrative identity and openness (see Randall, 2012; Purves et al. 2011).

Leonard's narrative was the only one which did not begin with a low narrative mood, instead starting at 'the high point'. One interpretation of this is that Leonard, who was diagnosed with dementia five years previously, may have a greater level of memory impairment than others and cannot recall earlier parts of his story. Alternatively, an interpretation informed by the resilience literature is that in Leonard's experiences, resilience represented more of a trait-like protective buffer (Ong et al., 2009); although Leonard acknowledged limitations associated with dementia, he was able to minimise these to maintain a relatively high narrative mood throughout. Leonard's narrative reminds us of the importance of hearing each individual's story and of not assuming that a diagnosis of dementia is always experienced as adversity in itself (Angus & Bowen, 2011).

Limitations

This study's findings cannot claim generalisability but do provide insights into how resilience narratives might be constructed in living with dementia. Our purposive sampling strategy (seeking people able and willing to discuss their experience of resilience) meant that participants generally had strong social support networks and attended at least one support group. Most participants requested that their spouses were present in their interviews, perhaps indicating that aspects of couple-hood (Hellström, Nolan & Lundh, 2007) interacted with how participants' resilience narratives were constructed and expressed.

Since such social resources represent protective factors and are likely to have influenced participants' accounts of experiencing resilience, people living with dementia who do not have (or cannot access) such resources could have very different stories to tell and this warrants further research. Additionally, all of our participants were white and British. The findings may therefore not reflect how resilience is storied by people with dementia across different cultures.

Narratives were retrospective and cross-sectional, meaning that we captured stories at one point in time. Future longitudinal narrative research will enable exploration of perceptions at various time points, allowing us to consider how narratives may evolve over time. It is also important to acknowledge that our interpretations of the resilience narratives may not have concurred fully with what participants meant, as we cannot objectively 'know' that participants were all relating to or understanding resilience in similar ways. Narratives involve intentionality and purpose (Harris, 1989); therefore, asking people to think about resilience and relate stories linked to it is always going to involve reconstruction and subjectivity.

Cognitive ability was not assessed within this study, but it is likely that as dementia progresses changes in communication style and ability make verbal narratives more difficult to share. Finding creative ways to explore resilience in older people living with more advanced stages of dementia, for example through the use of creative arts, could provide insight into the 'what happened next?' aspects of participants' narratives that were not captured within this study.

Conclusions

In this study resilience was storied by people living with dementia as a dynamic experience emerging within a context of adversity but not defined by it. Resilience stories developed over time following diagnosis. They contained considerable uncertainty as well as an ongoing interplay between positive and negative aspects of people's particular lived experiences. However, common themes in people's narratives related to agency, identity, optimism and connectedness and these themes indicate the ways in which resilience in living with dementia might be facilitated. This research demonstrates the richness of a narrative approach and the potential it has to help people express and retain possession of aspects of autobiography that are linked with personal strengths, assets and resources. If we listen closely, through narrative we can collaborate with people who have dementia to more fully understand the 'story' of well-being as it is lived.

Declaration of conflicting interests

None to declare.

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